UNIVERSITY OF CAPE COAST

# LIVED EXPERIENCES OF WOMEN WITH OBSTETRIC FISTULA IN THE WA MUNICIPALITY

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2019

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# LIVED EXPERIENCES OF WOMEN WITH OBSTETRIC FISTULA IN THE WA MUNICIPALITY

BY

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A thesis submitted to the School of Nursing and Midwifery, College of Health and Allied Sciences, University of Cape Coast, in partial fulfillment of the requirements for the award of Master of Nursing

MAY 2019

# DECLARATION

## Candidate's Declaration

I hereby declare that this thesis is the result of my original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature: …….. Date ……

Name:……..

## Supervisor's Declaration

I hereby declare that the preparation and presentation of the dissertation were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast

Principal Supervisor's Signature:  Date:31/07/2019

Name: Dr Jerry Paul Ninnoni

Co-Supervisor's Signature:…… Date:……

Name: Dr. (Mrs.) Evelyn Asamoah Ampofo

## ABSTRACT

Obstetric fistula is one of the most devastating conditions associated with childbirth globally. It is more prevalent in developing countries including Ghana. Estimates are that over 2 million young women live with untreated obstetric fistula in Asia and sub-Saharan Africa. Yet little is known about this phenomenon in Ghana. The study explored the lived experience of women with obstetric fistula in the Wa Municipality. A qualitative approach using descriptive phenomenology design was adopted for this study. Twelve participants were interviewed and the data analyzed thematically. The findings revealed that women living with obstetric fistula experience negative physical, socio-economic and psychological problems. These problems include; leakage odour, genital sore and paralysis, social isolation, diminished religious activities, transport challenges, lack of love, and intimacy. Others include; reduced self-esteem, anxiety, stigma and divorce. Coping strategies reported by participants included; Support from loved ones and the use of perfumery and diapers. Obstetric fistula is a neglected health condition with significant impacts on quality of life. Women in deprived communities are most affected and are often untreated with no access to health care.

**KEYWORDS**

Coping Strategy

Lived Experiences

Obstetric Fistula

## ACKNOWLEDGEMENTS

My heartfelt appreciation goes to my supervisors Dr. Jerry Paul Ninnoni and Dr. Mrs. Evelyn Asamoah Ampofo for their gentle guidance and precious support at each step of my thesis. Their critical review, comment, input, and recommendation guided me throughout this project. In addition, their timely response to my correspondences provided me with the atmosphere to succeed. I am also particularly indebted to my brother Mr. Linus Baatimia, your contributions were very useful, and this work would not have been possible without your inputs. Special thanks to Dr. Banabas Naa Gandau the fistula specialist and the director of Regional Hospital Wa, for his willingness and positive responses that facilitated this study. My profound gratitude to the nurses and participants for their precious time and knowledge.

Finally, to my dear husband, I never would have found my way without you. Your endless words of encouragement, unwavering support, and love throughout this journey have helped me to reach this far. Thank you.

## DEDICATION

I dedicate this work to the God Almighty who gave me the wisdom and the strength to carry out this important exercise from the beginning to the end. This work is also dedicated to my lovely mother (Madam Francisca Naatuo) and children; Wakilat, Raadi, and Pugumwin.

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| | |
|---|---|
| ECO | Emergency Obstetric Care |
| ESM | Ecological Systems Model |
| FGM | Female Genital Mutilation |
| IBD | Inflammatory Bowel Diseases |
| IDI | Indepth Interview Guide |
| OBF | Obstetric Fistula |
| QOL | Quality of Life |
| RVF | Rectovaginal Fistula |
| VVF | Vesicovaginal Fistula |
| WHO | World Health Organization |

# CHAPTER ONE

# INTRODUCTION

## Background of the Study

Obstetric fistula (OBF) is directly linked to one of the major causes of maternal mortality and obstructed labour. The World Health Organisation defines obstetric fistula as an abnormal opening between the vagina and bladder and/or rectum through which urine and/or faeces continually leak (Barageine, Beyeza-Kashesya, Byamugisha, Tumwesigye, Almroth, & Faxelid, 2015). Molendijk, Peeters, Baeten, Veenendaal, & van der Meulen-de, (2014) also view fistula as an abnormal connection between an organ and another structure as a result of the tie of the organ to the bladder. Fistulas develop when an organ becomes inflamed or injured. They are very common complications of inflammatory bowel diseases (IBD), occurring more frequently in Crohn's disease than ulcerative colitis. They are especially common when the colon and rectum are involved (Ozmeric, Bissada, Paes & da Silva, 2018; Vavricka et al, 2015). About 35 percent of people with Crohn's disease have at least one fistula (Adler, Ronsmans, Calvert & Filippi, 2013).

Classifications of fistula vary, but they generally include fistulae from obstetric causes including vesicovaginal fistula (VVF) and rectovaginal fistula (RVF). Fistulae have devastating consequences (Ruder, Cheyney & Emasu, 2018; Chessman, Verkerk, Hewitt, & Eze, 2017; Wall, Arrowsmith, Briggs, Browning & Lassey, 2005), particularly in low income countries where women have limited geographical and financial access to appropriate surgical care for the repair

compared to high-income countries where access to health care may be readily available.

Research findings estimate that more than 2 million young women live with untreated obstetric fistula in Asia and Sub-Saharan Africa (Demissie, 2017; Nnamuchi, Ezike, & Odinkonigbo, 2016; Barageine, 2015). Many of these are caused by prolonged and neglected obstructed labour (Bradley et al, 2017). Other factors causing fistulas include accidents, sexual abuse, and rape (Jina & Thomas, 2013; Badlani & Wall, 2009; Peterman & Johnson, 2009). Iatrogenic injury sustained during the course of delivery such as laparotomy, caesarean section, or through the use of forceps (Phillips, et al, 2018; Hilton, 2016). Dawson, et al, (2015) posit that severe forms of female genital cutting such as infibulations are often said to be possible contributors to the development of fistulas although there is little evidence in the world literature to support this belief.

The World Health Organization (WHO) looked at the relationship between female genital cutting and obstetric outcome. The study revealed that deliveries by women who have undergone Female Genital Mutilation (FGM) are significantly more likely to be complicated by caesarean section, postpartum haemorrhage, episiotomy, extended maternal hospital stay, resuscitation of the infant, and inpatient perinatal death than deliveries to women who have not had FGM (United Nations Office of the High Commissioner for Human Rights, 2008). Goh and Browning, (2005) also posited that traumatic fistulas are caused by violence against women in war-torn areas in Africa, such as the Democratic Republic of Congo, Sierra Leon, Sudan, and Somalia (Goh & Browning, 2005).

The prevalence of traumatic fistulas in these areas is difficult to determine with accuracy. Meanwhile, Goh and Browning, (2005) reported that many women with fistulas claimed a history of sexual abuse although this is difficult to ascertain. Other scholars (Gatwiri, 2019; Bellows, Bach, Baker & Warren, 2015) have also added that health problems with direct associations with fistula can lead to lifelong social and psychological problems involving ostracism, stigma, and shame. Women may be isolated from their family and community, divorced, or unable to work or participate in community events because of their condition. Fistula is also associated with sexual, fertility, and childbearing concerns (Pope, Ganesh, Chalamanda, Nundwe & Wilkinson, 2018; Mouriquand, et al, 2016; Gottvall & Waldenström, 2002).

In the context of Ghana, obstetric fistula (OBF) is regarded as a condition mostly associated with prolonged obstructed labor where emergency obstetrical care is often unavailable (Semere & Nour, 2008). A total of 1,538 women were reported to be assessed for OF in Ghana between 2011 and 2014 with the highest number of consultations occurring in the Northern region (Ghana Health Service, 2015). Although OBF can be surgically repaired or treated (Jarvis, Richter, Vallianatos & Thornton, 2017; Avevor, 2013), life following the repair can have intense emotional, social, and economic ramifications for women and their families (Yeakey, Chipeta, Rijken, Taulo, & Tsui, 2009) and often includes the loss of an unborn child (Cowgill, Bishop, Norgaard, Rubens, & Gravett, 2015).

Furthermore, these women live in a state of distress and fear of their future life. The condition often has a devastating impact on affected women and their

families and this may be due to the uncontrollable leakage of urine and/or feces and the accompanying smell (Sullivan, 2014; Abokaiagana, 2010). Fistula also limits women opportunities to earn a living and thus, worsens their economic status (Jarvis, Richter & Vallianatos, 2017). Moreover, in nearly every case of fistula, a baby is stillborn. An obstetric fistula may also lead to a future inability to conceive. The death of the baby, inability to conceive, and the stigma that accompanies fistula results in significant emotional damage (Jarvis, Richter & Vallianatos, 2017; Mwini-Nyaledzigbor, Agana & Pilkington, 2013; Alio et al, 2011).

Despite the adverse effects, fistulas patients go through many of these mothers are affected by a variety of factors including culture. Obstetric care may be geographically or financially unavailable, making home delivery the preferred choice over facilities and thus increases the risks of developing OBF. Also, timely referral systems for emergency obstetric care may be lacking and the individual may not be able to make decisions when care is urgently needed (Gameiro, 2017; Lewis & De Bernis, 2006). Barriers to care for expectant mothers are being mirrored in women with fistula. For example, a poor, rural, pregnant woman may be unable to afford transportation for birth in a medical facility and may be similarly unable to access transportation to a facility if she develops a fistula during delivery (Obasi, 2013). Again, the voices of women who have experienced obstetric fistulas are mostly missing in the literature especially in Ghana and within the Wa Municipality where this study was conducted. This study addresses this gap by presenting the perspectives of women who live with the condition.

The study seeks to document the plight of women with obstetric fistulas in their voices, deepens insight into the nature of this devastating problem, and thus serves as a resource for researchers, policymakers, and health care professionals concerned with reproductive health.

**Statement of the Problem**

While much progress has been made worldwide in improving maternal health, particularly in ensuring safe and successful childbirth, enormous disparities continue to persist between the developed and developing world (World Health Organization. 2016). On a global scale, the occurrence of chronic incidence of obstetric fistula in low-resource settings is one of the most visible indicators of this disparity between wealthy and poor. It is estimated that more than 2 million young women live with untreated obstetric fistula in Asia and sub-Saharan Africa (WHO, 2016) including Ghana. However, treatment capacity is limited to approximately 6,000 to 7,000 women per year (Royal College of Midwives, 2011).

According to the WHO, (2013), 15 percent of all pregnancies result in direct obstetric complications. Between the periods of 2011 and 2014, 1,538 cases of OBF were recorded in Ghana (UNFPA, 2015; GHS, 2015), only 40% of the cases were repaired. Although, the condition prevails in all 10 regions of Ghana, the Northern part of Ghana has the highest prevalence, followed by Ashanti, Western, and Central. Despite the national prevalence of obstetric fistula, there are currently only three main hospitals that offers dedicated OBF care. They are Mercy Women's Catholic Hospital at Mankessim-Central Region, Tamale Fistula

Center, and Tamale Central Hospital all in the Northern Regions (Sullivan, 2014). Despite these centers awareness and availability of these patients for repair is seen to be low.

Studies on fistula have also revealed that untreated OBF leads to severe medical, psychosocial, and economic consequences, which include divorce, neglect, and isolation by family and community owing to the uncontrollable seepage of urine and or faeces and the associated smell (Mselle & Kohi, 2015). It also increases poverty since it leaves women with few opportunities to earn a living. Moreover, in nearly every case of fistula, a baby is stillborn, and this may lead to future inability to conceive. Infertility may be a result of the traumatic labour as is a stillbirth. These factors increase vulnerability to stigma, resulting in emotional stress (WHO, 2014).

Meanwhile, scholarly studies in Ghana are mainly geared toward management of fistula (Bodner-Adler, Hanzal, Pablik, Koelbl & Bodner, 2017; Wall, 2012; Fofie & Baffoe, 2010; Miller, Lester, Webster & Cowan,2005) and reintegration of women post obstetric fistula repair (Jarvis, Richter, Vallianatos & Thornton, 2017). Regardless of the growing consensus about the indispensable attitude people exhibit towards fistula clients across the globe, there is also limited information about its scale prevalence rate, the barriers to implementation, and the feasibility of up-scaling its implementation across and within countries. Such formidable challenges, which if not addressed will continually increase the stigma and social isolation these patients face.

This debilitating condition has left and continues to leave hundreds of thousands of women suffering in solitude and shame. Obstetric fistula is undeniably one of the most telling examples of inequitable access to maternal health care and until recently, one of the most hidden and neglected conditions within the Northern part of Ghana. Thus, the need to conduct this study to explore the lived experiences of women with obstetrics fistula owing to the current high incidence rate within this region. This study, therefore, seeks to increase the knowledge about the condition and document the agony these women endure while living with the condition. The study will further, provide strong substantial evidence for policies to be developed to support these women.

**Purpose of the Study**

The main purpose of this study is to explore the lived experience of women with obstetric fistula in the Wa Municipality.

**Research Objectives**

1. To describe the lived experiences of women with Obstetric fistula
2. To investigate the impacts of obstetric fistula on quality of life
3. To explore women's coping strategies living with obstetric fistula

**Research Questions**

1. What are the experiences of women living with obstetric fistula?
2. How do their lived experiences affect their quality of life?
3. What coping strategies do women with obstetric fistula have?

**Significance of the Study**

The findings of this study would provide information to improve and strengthen the packaging and delivery of programs, activities, and messages on obstetric fistula to sharpen and enhance the level of awareness of Obstetric Fistula. In addition to that, it would help to foster behavior change regarding the condition. The findings would also be used to develop strategies that would encourage women with obstetric fistula and their families to access obstetric fistula repair services, to prevent the occurrence of the condition. The finding will also serve as a baseline for other studies to be conducted concerning to the subject.

**Delimitations**

Despite the scope and significance of the study; the study is confined only in one district and some selected communities as such findings cannot be generalized to the whole of Ghana.

**Limitations**

Notwithstanding the aforementioned contributions of this study to empirical knowledge, it has some limitations. The study used qualitative techniques in investigating issues of fistula and thus the findings cannot be generalized. Furthermore, the findings as reported pertain to only fistula clients found within Wa Municipality. Any other person who has lived experience of fistula and is not found in Wa Municipal was exempted from the study.

**Definition of Terms**

Obstetric: Anything pertaining to pregnancy, labour, and delivery

Fistula: An opening between two organs

Obstetric fistula: Is a childbirth injury, usually occurring when a woman is in labor too long or when delivery is obstructed, and she has no access to a cesarean section. She suffers internal injuries that leave her incontinent, trickling urine and sometimes feces through her vagina.

Lived Experience: Anything or situation women with obstetric fistulae go through as a result of the condition be it physical, psychological, social-economical or medical

Woman: Females of the reproductive age and above (15 years and above)

Coping strategy: Any measures employed by the women in order to contain their situation or endure the effects of the fistula on them.

**Organisation of the Study**

This study was organised into five chapters. Chapter one consists of the background to the study, the problem statement, the study objectives, research questions, as well as the significance of the study, limitations, delimitations and organization of the study. Chapter two deals with the review of relevant literature. This was covered under the following sub-topics: The concept of Obstetric Fistula and its causes, various experiences with obstetric fistula, and lastly coping responses with obstetric fistula. Chapter Three highlights the methodological approaches used. It focuses on the study area characteristics, and research design, target population, sampling and sampling size, study instrument, source of data,

data collection, data management, and analysis as well as ethical considerations. Chapter Four consists of the findings and discussions. The chapter describes and discusses issues such as the demographic background of mothers; various experiences with obstetric fistula, how it affects their quality of life and the coping responses with obstetric fistula. The last chapter covers the conclusion, a summary of major findings and recommendations of the study.

# CHAPTER TWO

# LITERATURE REVIEW

## Introduction

This chapter presents a review of relevant literature on the lived experience of women with obstetric fistula in the Wa Municipality. Specifically, the study describes women's experiences of living with obstetric fistula, investigate how it affects their quality of life and to explore women's coping strategies for living with obstetric fistula. A literature review is conducted using online academic databases of current Medical journals such as EBSCO host, Hinari, Pubmed and Google Scholar. Search terms used include various combinations of obstetric fistula, reproductive health, and obstetric health. A conceptual framework was developed based on the literature found on the lived experiences of women living with obstetric fistula. Again, an empirical review was conducted based on the research objectives. Finally, a conclusion was made based on the findings from the literature review.

## Theoretical Perspectives

The theoretical perspectives underpinning the study are the transactional model of stress and coping, Stigma Theory and Ecological Systems Model. These theories and how they inform the study are discussed in details in the proceeding paragraphs. Baker and Intagliata, (1982) on quality of life (QOL) was deem fit for the study to situated

**Transactional Model of Stress and Coping**

The transactional model of stress and coping explains how people cope with stressful events. When people are confronted with stress, they evaluate the significance of a stressor as stressful, positive, controllable, challenging, or irrelevant. This prompts efforts to cope with the stressor. However, according to this model, an increased perception of risk can also generate distress (Wenzel, Glanz, Lerman, 2000) When people face stress, they evaluate not only the features of the stressful situation but also what they can do about it. They assess their perceived ability to change the situation and manage their emotional reaction to the threat. This will be mediated by actual coping strategies (Wenzel, Glanz, Lerman, 2000)

This model conceptualizes coping efforts along two dimensions, that is problem-focused and emotion-focused coping strategies. Problem management strategies, which will be more adaptive for stressors that are changeable, are directed at changing the stressful situation. These include active coping, planning problem solving, information seeking, and use of social support. Emotion-focused coping efforts, which are more suitable when the stressor is unchangeable, are directed at changing the way one thinks or feels about a stressful situation. These include seeking of social support, venting of feelings, avoidance, and denial (Mselle, Evjen-Olsen, Moland, Mvungi, Kohi, 2012)

On the same vein, women living with obstetric fistula are challenged with some type of constraint including active coping, planning problem solving, information seeking, and use of social support especially moments when they are

confronted with stress. They evaluate the significance of a stressor as stressful, positive, controllable, challenging, or irrelevant since they are choice less to options at hand especially moments when the experiences, they are confronted with are stressful.

**Stigma Theory**

Social stigmas can occur in many different forms. The most common deal with culture, gender, race, illness, and disease. Individuals who are stigmatised usually feel different and devalued by others. Stigma may also be described as a label that associates a person to a set of unwanted characteristics that form a stereotype. It is also affixed (Jacoby, Snape, Baker 2005). Once people identify and label your differences others will assume that is just how things are and the person will remain stigmatised until the stigmatising attribute is undetectable. A considerable amount of generalisation is required to create groups, meaning that you put someone in a general group regardless of how well they actually fit into that group. However, the attributes that society selects differ according to time and place. What is considered out of place in one society could be the norm in another. When society categorises individuals into certain groups the labeled person is subjected to status loss and discrimination (Jacoby, Snape, Baker 2005). Society will start to form expectations about those groups once the cultural stereotype is secured.

According to Goffman's theory of social stigma, a stigma is an attribute, behavior, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable,

rejected stereotype rather than in an accepted, normal one. Goffman, a noted sociologist, defined stigma as a special kind of gap between virtual social identity and actual social identity.

The stigmatised are ostracized, devalued, scorned, shunned and ignored. They experience discrimination in the realms of employment and housing (Page, 2009). Perceived prejudice and discrimination is also associated with negative physical and mental health outcomes (Williams, Neighbors & Jackson, 2003). Young people who experience stigma associated with mental health difficulties may face negative reactions from their peer group (Dolphin & Hennessy, 2014; Dolphin & Hennessy, 2016; Dolphin & Hennessy, 2017; O'Driscoll, Heary, Hennessy & McKeague, 2012). Those who perceive themselves to be members of a stigmatised group, whether it is obvious to those around them or not, often experience psychological distress and many views themselves contemptuously (Heatherton, Kleck, Hebl & Hull, 2000).

Although the experience of being stigmatised may take a toll on self-esteem, academic achievement, and other outcomes, many people with stigmatised attributes have high self-esteem, perform at high levels, are happy and appear to be quite resilient to their negative experiences (Heatherton, Kleck, Hebl & Hull, 2000). There is also "positive stigma": it is possible to be too rich, or too smart. This is noted by Goffman (1963:141) in his discussion of leaders, who are subsequently given license to deviate from some behavioral norms because they have contributed far above the expectations of the group. This can result in social stigma.

The study applied the stigma theory, as described by Goffman (Goffman 1963), and the coping theory by Lazarus, kanner and Folkman (1980), to discuss the experiences of women when they live with fistula. Stigma was used with regard to the way women perceived their lived experiences. The paper also explores the way women coped in their daily lives with this stigmatising condition.

Goffman defines stigma as "an attribute that is significantly discrediting" (Goffman, 1963). Within the social process, a stigmatised person possesses an "undesirable difference" or "deviance" (Goffman, 1963). Stigma is a constantly changing social process that occurs when five interrelated components converge: namely "labelling", "stereotyping", "separation", "status loss and discrimination" and the playing out of "social and political power" (Link & Phelan, 2001). Discrimination can be individual, structural or self-imposed (Link & Phelan, 2001; Mahajan et al., 2008). Anthropologically, the concept of stigma remains empty and decontextualized if not filled with meaning from people's lived experiences (Kleinman et al., 1995). Stigmatisation is a pragmatic response to "perceived threats, real dangers, and fear of the unknown" (Yang et al., 2007) and can either be enacted or felt. Enacted stigma refers to the unfair treatment of others towards the stigmatised person, including discriminatory attitudes and acts of discrimination; whereas felt stigma refers to the stigmatized person's internal feelings of shame (self-stigma) and fear of discrimination (perceived stigma) (Sayles et al., 2008).

Coping occurs in response to a stressful situation and is usually initiated by activities or changes aimed at maintaining one's mental health and emotional wellbeing (Carver, Scheier, & Weintraub, 1989). Lazarus, Kanner and Folkman (1980) developed a measure called "Ways of Coping", which consists of predicates, each of which portrays a coping thought or action that people engage in when under stress (Carver, Scheier & Weintraub, 1989). Two general types of coping are problem-focused coping and emotion-focused coping (Folkman & Lazarus, 1980). Problem-focused coping is aimed at problem-solving or the effort to alter the source of stress, while emotion-focused coping is aimed at reducing or managing the emotional distress associated with the situation. Most stressors elicit both types of coping, but problem-focused coping predominates when people feel that something constructive can be done; emotion-focused coping, on the other hand, predominates when people feel that the stressor is something that can be endured (Folkman & Lazarus, 1980; Carver, Scheier & Weintraub, 1989).

**Ecological Systems Model**

Bronfenbrenner's theory defines complex "layers" of the environment, each influencing a child's development (Paquette & Ryan, 2008). Bronfenbrenner (1979) refers to the ecology of human development as involving "the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings which, the developing individual person lives" (p. 21). The environment is seen as a series of nested structures, which include, but transcend, home, school, and the neighborhood settings within which developing individuals spend their daily lives (Scott, 2015). In this model,

persons living with fistula is seen as emerging from the person interactions and interdependencies within the hierarchically arranged, multiple-level ecological contexts (Krasny, Lundholm & Plummer, 2010). The layers within the ecological model include the individual, microsystem, mesosystem, exosystem, macrosystem, and chronosystems, all in concentric circles (Leonard, 2011). The issues at the individual level encompass the individual psychological and personal historical characteristics of the condition (example, that influence behaviour change, including risk factors (Biological, socio-demographic and physical factors), gender, age, religious identity, Marital sex, economic status, values, life goals and expectations, stigma, and coping).

**Microsystem**

This is the layer closest to the patient and contains the structures with which the patient has direct contact especially is ‘a pattern of activities, roles, and interpersonal relationships experienced by the developing person in a given setting with particular physical and material characteristics (Paquette & Ryan, 2008). The microsystem, therefore, encompasses the relationships and interactions the patient has with her immediate surroundings (Araujo, Davids & Hristovski, 2006). The structures in the microsystem include Formal (and informal) social networks and social support systems that can influence individual experience, including family, spouse, friends, peers, religious networks, customs or traditions. This also extends to support, communication, resources and stigma influence. At this level, relationships have an impact in two directions - both away from the patient and toward the patient. For instance, fistula patient parents may

affect his beliefs and behavior; however, the patient also affects the behaviour and beliefs of the parent. Bronfenbrenner calls these bi-directional influences, and he shows how they occur among all levels of the environment (Paquette & Ryan, 2008).

**Mesosystem**

The layer of the mesosystem concerns the interactions among several microsystems within which fistula patient shift among various roles as a result of moving between one microsystem to the other (Bronfenbrenner, 1979). This layer also provides the connection between the structures of the fistula patients microsystem (Paquette & Ryan, 2008). For instance, the connection between the fistula patient and his or her parents or between his church, close friends and his neighborhood.

**Exosystem**

The exosystem defines the larger social system in which the fistula patient does not function directly but impacts patient development by interacting with some structure in her microsystem (Paquette & Ryan, 2008). In other words, it is the social setting that indirectly affects patient when they interact with some structures in their microsystem (Araujo, Davids & Hristovski, 2006). This implies that persons living with obstetric fistula are not directly participating or involved in these social settings, but the process and experiences there affect their development. For instance, as parents' workplaces, their religious institutions, and health and welfare services in the community. The patient living with fistula is not

involved in the parent's place of work but events in the workplace of the parent can affect the relationship between the parent and the person living with fistula.

**Macrosystem**

The macrosystem may be considered the outermost layer in the patient's environment comprising cultural values, customs, and laws (Benjamin, 2010). The priority this system gives to patient needs to affect the support they receive at inner levels of the environment (Benjamin, 2010). Thus, opportunity structures and life-course options for the child exist within this system (Araujo, Davids & Hristovski, 2006). For instance, if the culture in a particular society does not encourage good parent and child to interact with the patient, this act will either put more emotional pressure on the patient since he or she will be thinking about life and probably considering suicide as the last option. Certain cultural beliefs also see these people as cues to society such as public isolation is their punishment. This to a larger extent reduces their feelings and challenges to themselves.

**Chronosystem**

The chronosystem covers the socio-historical conditions, transitions, and changes in individuals and their environment across time. Thus, it reflects the dynamic environmental transitions, encompassing entries, exits, milestones, and turning points over time in the life of the child (Bronfenbrenner& Morris, 2006). Elements within this system can be either external, such as the timing of a parent's death, or internal, such as the physiological changes that occur with the aging of a child. For instance, as children get older, they may react differently to

environmental changes and may be able to determine how that change will influence them.

This theory is considered suitable for this study because it has the ability to explain the experiences of women living with obstetric fistula, the experiences of spouses living with a wife with fistula and efficacy and acceptability of early discharge with a catheter following surgical repair of urogenital fistula. Within the social-ecological framework, we nest stigma and coping theories and the hegemonic masculinity to explain the experiences of women with fistula and that of the men whose wives have fistula respectively.

The ESM framework recognises that health experiences and outcomes are often influenced by factors situated within and beyond the individual, in this case, a woman with fistula (Stokols, 1996; Feldacker, Ennett, & Speizer, 2011; Centers for Disease Control and Prevention, 2015) Implicit within this model is the concept of a dynamic interaction between the various factors whose equilibrium ultimately defines the overall health experiences (Elder et al, 2006), in this case of living with fistula.

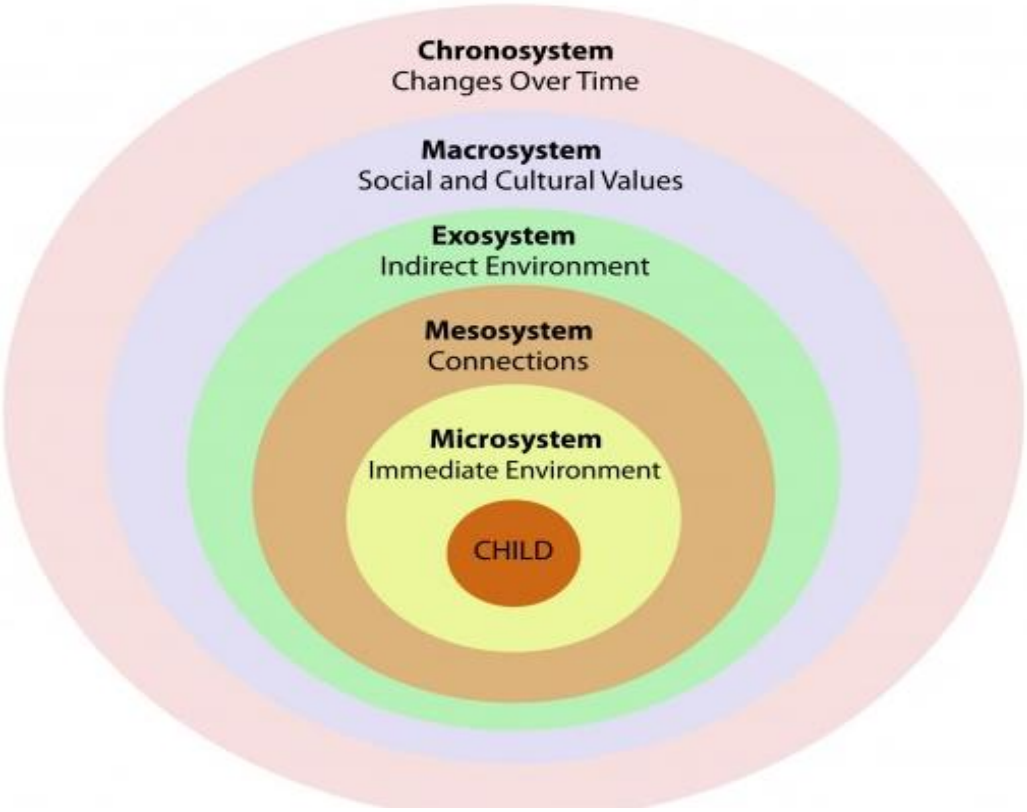


*Figure 1*: Ecological Systems Model

Source: Bronfenbrenner's (1979)

**Conceptual Framework**

Although the above theories appear to have some connection with the phenomena under study, Baker and Intagliata (1982) model on quality of life (QOL) was deemed fit for this study. The framework clarifies relationships between external environments, individual experience, individual health status and quality of life responses, which may help to point out some differences between the various approaches to the assessment of the quality of life.

This model assumes four separate application of interest as related to the quality of life assessment; 1) focus 1 is referred to as "environmental system'' mainly concerned with relating the objective indicators such as the physical,

socioeconomic, and cultural environment, 2) focus II is denoted as "experienced environment", which concerns what goes on within the person, since perceived attributes of the physical environment differ from individuals, 3) the focus III, stated as the "bio-psycho system" signifies the actual state or degree of health and well-being of an individual and, 4) focus IV resolute with the "behavioral outcomes" particularly how individuals cope, adapt and deal with unpleasant situations (Baker & Intagliata, 1982). Zautra and Goodhart (1979) stipulated they do not only pursue to do away or adjust to painful life experiences but they also actively seek to increase skills, competence and to change the environment.

The framework encompasses the three objectives under investigation in the study; the quality of life of women with an obstetric fistula on the left side, lived experience of women with obstetric fistula (Life condition and events as perceived) in the middle and the coping strategies on the right side. Thus, the quality of life of women living with obstetric fistula in the framework answers the first objective, which seeks to examine how the disease condition affects patient's wellbeing in terms of physical, socioeconomic, physiological and culture.

Health problems that may arise could be a disease-specific effect of physical wellbeing such as discharge of urine/faeces, body odour, and fitness. The socioeconomic involves the interaction of the obstetric fistula patient with others. The parameters under the socioeconomic are social and economic activities, such as isolation, inability to work, divorce and stigmatization. The psychological refers to the emotional functioning of the obstetric fistula patient example self-

esteem, sense of purpose, depression, and anxiety. Culture refers to the patient personal beliefs and attitudes

The lived experience of women with fistula refers to Life conditions and events as they are perceived by the patient. Obstetric fistula patient may experience material challenges such as housing, nutrition, financial and transportation as well as social and religious interactions. These lived experiences can be influenced by the dimensions of quality of life in the framework which includes physical, socioeconomic, psychological and cultural.

The last construct on the framework which is coping strategies measures the third objective of this study which describes the coping strategies of women living with obstetric fistula. This is conceptualized from the point of view that, the patient lived experiences influenced her coping strategies. On the other hand, whether the coping strategies are positive or negative, they will also intend to influence the patient quality of life.

This framework was adapted from Baker & Intagliata model of quality of life models (1982). This model is considered because it consists of domains which were suitable for generating the appropriate information to meet the objectives of the study (figure 2).

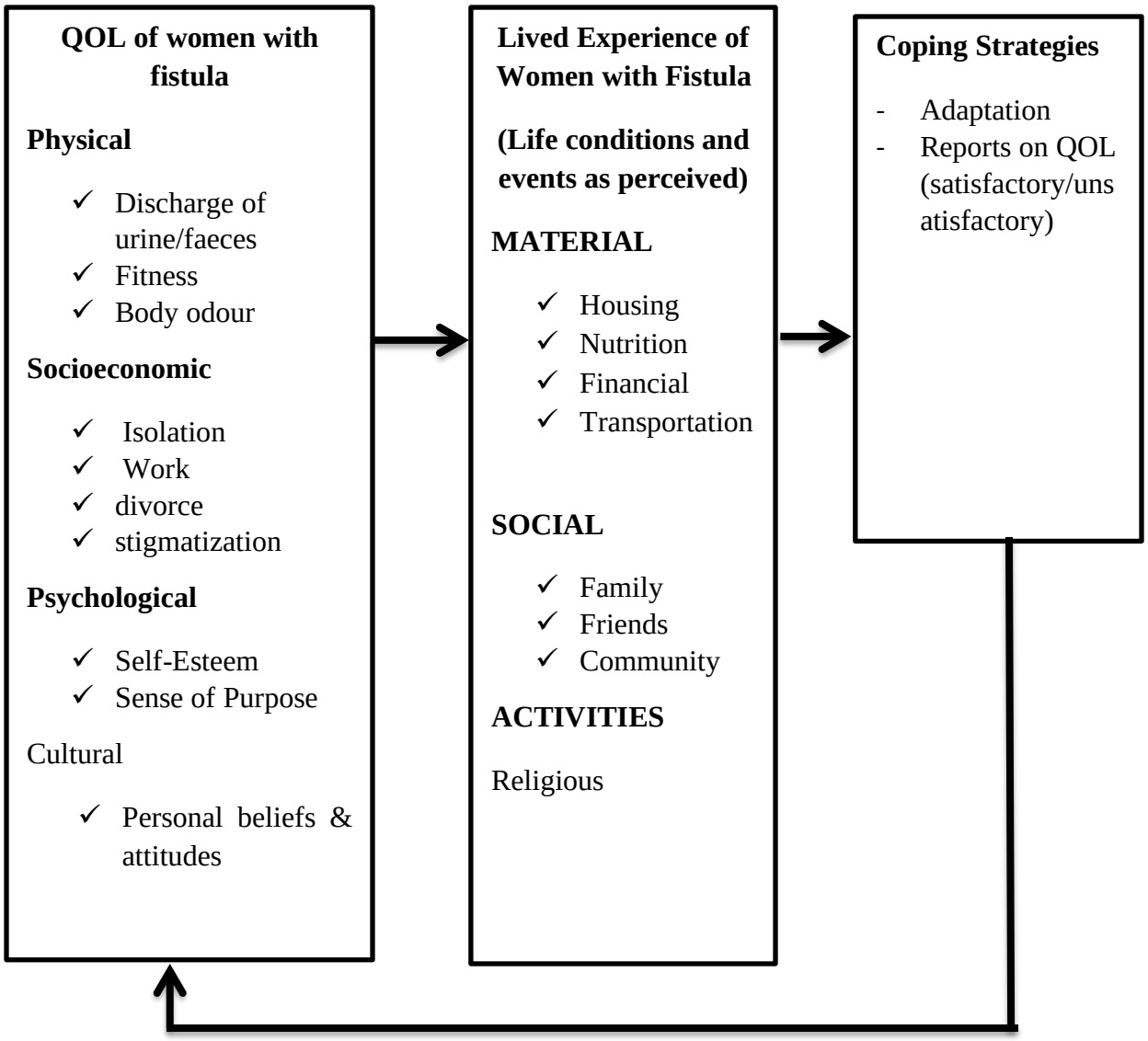


*Figure 2:* A conceptual framework Adapted from quality of life (QOL) model (Baker & Intagliata, 1982)

**The concept of Obstetric Fistula and its causes**

Kimani (2014) defined Obstetric Fistula as an abnormal communication created between the vagina and the bladder and or the rectum. Khisa et al. (2012) explain that Obstetric Fistula occurs mainly due to prolonged and obstructed labor. A study by Donnay (2005) and Women Dignity Project (2006), which is the primary Non-Governmental Organization dealing with Obstetric Fistula in Tanzania in collaboration with the Ministry of Health, defined Obstetric Fistula as: a hole or false communication that forms between the bladder and vagina known as a Vesical Vaginal Fistula (VVF) or between the rectum and vagina Recto Vaginal Fistula (RVF) during prolonged labor and obstructed labor. The constant pressure of the fetal skull (the baby's head) against the soft tissue around the vagina and the bladder and/or rectum cuts off the blood supply to the tissues, causing them to disintegrate (ischemic necrosis). A hole is then left, and urine and/or feces leak continuously and uncontrollably from the vagina. In nearly all cases of Obstetric Fistula, the baby dies.

**Causes of Fistula**

In spite of available evidence that obstetric fistula is preventable and has a high success rate of repair and evidence of its eradication in North America and Europe, many women continue to suffer from the condition. Although it is clear that the major factors that make women prone to developing the condition are avoidable, many women and men alike are ignorant about them (Bossola, et al., 2018; Salako et al., 2018; Zhou, Chen, Qiao, Chen & Zong, 2017). It, therefore, behooves on the health care delivery services to make efforts to provide relevant

health information, education, and communication activities to address these issues particularly those that promote maternal health and access to Emergency Obstetric Care (EOC). The issue of concern is that understanding of obstetric fistula continues to remain an unfamiliar phenomenon amongst the public.

Factors causing fistulas include accidents, sexual abuse, and rape (Jina & Thomas, 2013; Badlani & Wall, 2009; Peterman & Johnson, 2009). Iatrogenic injury sustained during the course of delivery such as at the time of laparotomy, caesarean section, or through the use of forceps (Phillips et al., 2018; Hilton, 2016). Dawson, et al. (2015) posited that severe forms of female genital cutting such as like infibulations are often said to be possible contributors to the development of fistulas although there is little evidence in the world literature to support this belief.

A recent study by the World Health Organisation looking at the relationship between female genital cutting and obstetric outcome found that "deliveries to women who have undergone FGM are significantly more likely to be complicated by caesarean section, postpartum haemorrhage, episiotomy, extended maternal hospital stay, resuscitation of the infant, and inpatient perinatal death, than deliveries to women who have not had FGM (United Nations Office of the High Commissioner for Human Rights, 2008). A recent review on the subject of traumatic fistulas caused by violence against women documents the presence of such cases in war-torn areas of Africa such as the Democratic Republic of Congo, Sierra Leon, Sudan, and Somalia (Goh & Browning, 2005). However, the prevalence of traumatic fistulas in these areas is sometimes difficult

to determine with accuracy as the authors report that many women with fistulas claim a history of sexual abuse even when this does not appear to be the case

**Experiences Women with Obstetrics Fistula Faces**

**Socio-Cultural Challenges**

Women with OBF are left with no choice than to cope with their situation (Kabayambi et al., 2014) in the absence of access to surgical repair. These coping strategies comprise eating and drinking only when it is needed, bathing regularly, using perfume and powder, putting calamine lotion on the sores surrounding the genitals and thighs, and using old pieces of cloth that are torn into shreds as pads (Ghana Health Service, 2015). These conditions affect their daily routine.

A qualitative descriptive study in Ghana exploring the experiences women who sustained obstetric fistula during childbirth, Mwini-Nyaledzigbor, Agana & Pilkington, (2013) finding reveals that cultural beliefs and practices surrounding prolonged labor in childbirth, barriers to delivering at a health care facility, and the challenges of living with obstetric fistula, including psychosocial, socioeconomic, physical, and health care access issues.

**Economic Experience**

In addition to the psychosomatic pain, it comes with, obstetric fistula also levies enormous monetary burdens on sufferers and their families. Lack of cash or draining of scanty resources, lack of family backing, and long distance to health facilities was some of the reasons why women living with OBF are not easy to locate as noted by Kazaura, Kamazima, & Mangi, (2011). The postponement of

OBF repair may equally expose patients to a diminished social, mental, medical, and emotional status due to the spiteful difficulties accompanying the faecal or urine incontinence. This may ultimately lead to social withdrawal or exclusion (Murray et al., 2002). The breakdown of marriages due to having OBF has been reported (Kabayambi et al., 2014). In addition, loss of children, seclusion, and lack of gainful employment are protuberant challenges, which increase the stress level for the affected women and could lead to loss of identity (Mselle et al., 2012). Beyond the individual woman, the families may also experience stigma due to the status of the woman with OBF. This is called caregiver stigma (Kabayambi et al., 2014; Jarvis et al., 2017).

Childbirth care is affected by a variety of factors including access, socio-economic resources, and culture. Obstetric care may be geographically or financially unavailable, home delivery may be common and preferred over facilities, while timely referral systems for emergency obstetric care may be lacking, and girls and women may lack decision-making power and agency for seeking care (Gameiro, 2017; Lewis & De Bernis, 2006). Many barriers preventing care for pregnant women and during labor are mirrored in women with fistula unable to access care. A poor, rural, pregnant woman may be unable to afford transportation for birth in a medical facility and maybe similarly unable to access transportation to a facility if she develops a fistula during delivery (Obasi, 2013).

**Psychological experience**

In addition to incontinence and other health problems with direct associations, fistula can lead to lifelong social and psychological problems involving ostracism, stigma, and shame (Gatwiri, 2019; Bellows, Bach, Baker & Warren, 2015). Women may be isolated from their family and community, divorced, or unable to work or participate in community events because of their condition. Community members may blame women living with fistula for their condition, viewing it as punishment for sin or venereal disease or curse. Consequently, fistula is also associated with psychosocial problems such as depression and anxiety, which may further contribute to the inability to seek treatment. Fistula is also associated with sexuality, fertility, and future childbearing concerns (Pope, Ganesh, Chalamanda, Nundwe & Wilkinson, 2018; Yeakey et al, 2009).

Among Malawian women, Yeakey et al, (2009), findings indicate that the experiences of Malawian women with fistula were more varied than anticipated. Concerning relationships with husbands and family, we found high rates of divorce and stigma, yet these outcomes were far from universal or inevitable. Many women, in addition to their families, discussed high levels of support from those individuals closest to them. Nonetheless, many women experienced the fistula as a direct assault on their ability to fulfill social expectations of them as women, wives, and mothers. Women identified fertility and continued childbearing as central concerns

Although there have been achievements in the surgical treatment of obstetric fistula, the long-term emotional, psychological, social and economic experiences of women after surgical repair have received less attention. Khisa and Nyamongo, (2012) study unearth that, woman in West Pokot, Kenya as part of their experiences reported continuing problems following corrective surgery, including separation and divorce, infertility, stigma, isolation, shame, reduced sense of worth, psychological trauma, misperceptions of others, and unemployment. Programmes focusing on the needs of the women should address their social, economic and psychological needs, and include their husbands, families and the community at large as key actors. It is also evidence in other low-income settings in Africa and Asia, with the general agreement that a fistula has negative social and psychological implications that result from its physical manifestations, and the fact that they are always noted for leaking urine and odour. The discrediting usually makes them feel different from other women and as such isolate from the rest of society (Wall et al, 2004, WHO, 2006, Bangser et al., 2011, Roush, 2009, Dahlgren, Emmelin, & Winkvist, 2004, Mwini-Nyaledzigbor et al., (2013). These situations are correlated with mental health problems (Kuo, Chen, &Tzeng, 2014).

A Kenya base study according to Mohameda, Amirb and Ng'ang, (2016) on the psychosocial effects of obstetric fistula on young mothers in Western Kenya shows that the main psychological effects of fistula were sadness, shame and loss of self-worth. The study also points at stigmatization, social worthlessness and isolation as the main social effects of fistula.

Debrework, Abebaw and Mezgebu (2018) also acknowledges that Women with fistula often experience adverse mental health problems such as depression, post-traumatic stress disorder (PTSD), hopelessness, fear of future life, loss of dignity and feelings of dependency. These often results from the stress of the condition, lack of support, social stigma, economical incapability, lack of knowledge about fistula treatment, people's comments and reactions, and the perceived causes.

Very high rates of depression with worse severity have been reported among African women with VVF and RVF which decrease their chances of seeking treatment (Siddle Mwambingu, Malinga & Fiander ,2013;Alio et al,2011; Weston, Mutiso, Mwangi, Qureshi, Beard & Venkat, 2011; Wegner, Ruminjo, Sinclair, Pesso, & Mehta,2007). An Ethiopian study found almost all women with fistula had depression compared to about two-thirds in patients with advanced pelvic organ prolapse (Zeleke, Ayele, Woldetsadik, Bisetegn, & Adane, 2013). Another study found significantly higher rates of depression, PTSD, somatic complaints and maladaptive coping among OF patients compared to other women attending gynecology clinic for other gynecological conditions (Wilson, Sikkema, Watt, & Masenga, 2015). Depression is commoner among older women, divorcee, unemployed, and self-perception of fistula as a severe problem, those without social support and those living with fistula for more than 3 months (Zeleke, et al, 2013; Weston, et al, 2011). Over half of women with OF in an Ethiopian study had suicidal ideations alongside other feelings such as shame,

loneliness and being devalued as a woman (Alio, et al, 2011; Muleta, Rasmussen & Kiserud, 2010).

A study done in Uganda found that nearly all the women with fistula experienced isolation, either they isolated themselves due to feelings of shame or were cut off from normal participation in their communities as a result of stigma surrounding the condition. They lacked self-confidence to participate in public activities such as funerals, weddings, community meetings and church services – for fear of wetting themselves and smelling badly in public, or they were not welcome to attend. They live a life of social outcasts, and some fall into deeper physical and emotional decline in addition are severely stressed and women with such feelings may resort to suicide (Women's Dignity Project and Engender Health 2006 and 2007).

Fistula leaves women with few opportunities to earn a living, their ability to work, or to work to their capacity, access to jobs, is limited and this increases their dependence on others (UNFPA, 2006). Denied family support, their poverty and malnutrition are frustrating. They may earn through begging and comparable stigmatising employment (Cook et al, 2004). The grief of losing a child and becoming disabled exacerbates the pain, and further, they may have to spend many years with no hope of getting surgical repair since few hospitals and surgeons are able to provide treatment. For many women, the social isolation they face is worse than the physical agony. The girls and women pregnancy and delivery experiences critically need light onto policies and interventions to

decrease maternal morbidity and mortality, as well as improve their health and wellbeing (Bangser, 2006).

**Effect of Obstetric Fistula on Participant Quality of Life**

A cross-sectional study according to Wilson, Sikkema, Watt, and Masenga, (2015) reveals that obstetric fistula patients reported significantly higher symptoms of depression, posttraumatic stress disorder, somatic complaints, and maladaptive coping. They also reported significantly lower social support.

Ahmed & Holtz, (2007) meta-analysis for two of the major consequences of having a fistula, divorce/separation, and perinatal child loss. Studies suggest that surgical treatment usually closes the fistula and improves the physical and mental health of affected women. Meanwhile, Yeakey et al, (2009), findings indicate that the experiences of Malawian women with fistula were found to have high rates of divorce and stigma, yet these outcomes were far from universal or inevitable. Pope, Ganesh, Chalamanda, Nundwe and Wilkinson, (2018) who posit that fistula as a condition is also associated with psychosocial problems such as depression and anxiety, which may further contribute to the inability to seek treatment due to that anxiety one builds within herself

Stigma was also revealed by studies as the prevailing effect confronted by fistula patients (Ansong, 2014). The word, Stigma is defined as an attribute that is deeply discrediting and that which reduces the woman from a whole and normal person to a tainted or discounted one (Goffman, 1963). Stigma was observed in three forms in this study: internal, external and caregiver. One type, internal stigma, occurs intra-personally when the stigmatized individual internalizes the

negative stereotype; for example, the woman living with OBF may tell herself, I am worthless; I am unclean (Link & Phelan, 2001).Watt et al., (2015), Wilson, (2015) and Rahm, Renck and Ringsberg, (2013) also point to the fact that women with obstetric fistula are socially stigmatised and marginalised, psychologically affected and economically deprived, and often suffer a traumatic birth experience

Studies in low-income countries, including Ethiopia, report that women with fistula have a significantly higher incidence of symptoms of depression, psychosocial dysfunction, and anxiety (Dennis et al., 2016). Clearly, there was much resentment, rejection, and disapproval of women with obstetric fistula. As such, it is like certain other illnesses and behaviors (e.g., mental illness, leprosy, tuberculosis, sexually transmitted diseases, HIV/AIDS, prostitution) that are considered disgraceful, and, thus, stigmatised, in Ghanaian society (Mwinituo & Mill, 2006).

A qualitative study by Animut, et al., (2019) at Bahir Dar Hamlin Fistula Center, Amhara Regional State, Ethiopia unearthed that bad odour arising from incontinence often results in negative social consequences, including divorce and ostracisation from society towards OBF patients which to a larger extent compromise their quality of life. The existing data suggest that large numbers of women with OBF become divorced or separated from their husbands, particularly when it becomes evident that their condition is chronic rather than transient. Successful repairs of the fistula are assumed to lead to a smooth reintegration when these women return home; however, they may still face problems

reintegrating into their local communities. Simply repairing the injuries is not the end of the challenge (Wall, Arrowsmith, Briggs & Lassey, 2001).

**Coping Strategies Women with Obstetric Fistula Adopt**

Women with obstetric fistula adopt coping strategies because of the physical and psychological impact obstetric fistula has on them, for many chronic illnesses coping strategies are essential for adaptation. Various strategies exist to assist people with different chronic illnesses including cancer but little is existent for obstetric fistula due to lack of in-depth study done in this area (Vloeberghs, Van der Kwaak, Knipscheer & van den Muijsenbergh, 2012). In a study done by women's dignity project and engender health USA in Tanzania, it was shown that women living with fistula dealt with the hardship of fistula through various coping mechanisms. The study revealed that nearly all of them said that they use painful problem solving, seeking social support. A minority of women mentioned that they coped by problem-focused coping such as seeking treatment. The other minor group of women mentioned that they isolate themselves by staying at home and or keeping their fistula a secret. Other coping mechanisms included: work, support by family, prayer and bible reading, and perseverance/self-determination (Women's Dignity Project and Engender Health, 2006).

Wang et al. (2014) in China in conjunction care seeking as an alternative to mute the condition, reveals that women with moderate internalised shame (stigma) have stronger intentions to seek care than those with low or high levels of internalised shame. Plumbmer, (2001), Morse (2000), also found that once

people have suffered enough and are able to accept their changed reality, they gain new insight and appreciation of life and their changed reality.

In studies done in Uganda and Tanzania, according to Skinner, Edge, Altman & Sherwood, (2003) finding have it that nearly all the women were supported by at least one person in their family or community. Only a few numbers of women did not receive any support or did not mention receiving support during their interviews. The types of support most frequently offered were food, soap, and money. Meanwhile, WHO, (2006) reports posit that coping mechanisms cited by women as they experience socially unaccepted condition fistula include isolating themselves by staying home, keeping their fistula a secret, working, being supported by the family, praying and reading the bible, and perseverance/self-determination.

**Chapter Summary**

This chapter dealt with early researches people explored and found in the area of fistula in Ghana as well as from other settings. The review touched on three board headings namely; empirical review, theoretical perspectives and conceptual issues.

The first part reviewed empirical findings of the study. Themes like the concept of Obstetric Fistula and its causes, causes of Fistula, experiences women with Obstetrics Fistula faces, effect of obstetric fistula on participant quality of life and Coping Strategies Women with Obstetric Fistula Adopt.

The second section of the review also systematically reviewed theories guiding the study. The theoretical perspectives underpinning the study are the

transactional model of stress and coping, Stigma Theory and Ecological Systems Model. These theories and how they inform the study are discussed into details in the proceeding paragraphs. Baker and Intagliata, (1982) modle on quality of life (QOL) was deep fit for the study to situated

# CHAPTER THREE

# RESEARCH METHODS

## Introduction

This section covers the study area, study design, data source as well as target population. It includes the sampling method and sample size, data collection instrument, data analysis, and ethical issues.

## Research Design

The study adopted a qualitative research method with the aim of exploring the lived experience of women with obstetric fistula within the study area. A qualitative design enables researchers to explore a social or human problem, builds a complex holistic picture, analyses words reports detailed views of informants, and conducts the study in a natural setting (Smith & Smith, 2018; Green & Thorogood, 2018). A qualitative research methodology is an umbrella term encompassing many approaches including case study, ethnography, action research, grounded theory, and narrative research (Smith & Smith, 2018). Based on the qualitative approaches, descriptive phenomenology design which has widely been used in nursing research as a method to explore and describe the lived experiences of individuals was adopted as the design for this study. The rationale for using this design is based on the fact that the design helps to explore the intentional relationship between persons and situations. It discloses the essence inherent in human experiences through imaginative variation (Giorgi, 2012; Englander, 2012; Todres, 2005).

**Study Area**

The study was carried out in the Wa Municipality, one of the eleven municipal and district assemblies in the Upper West Region of Ghana. The Municipality is located in the guinea savannah vegetation belt and shares administrative boundaries with Nadowli District Assembly to the north, the Wa East District to the east and the south to the Northern Region (Figure 3). Wa Municipality has a landmass of approximately 234.74 square kilometers, which is about 6.4% of the region (Wa Municipal Assembly, 2014).

According to the 2010 population and housing census reports, Wa municipality has a total population of 107,214. Out of the total population, 54,218 are females representing 50.6% as against 52,996 males representing 49.4% males (Ghana statistical service-GSS, 2012).

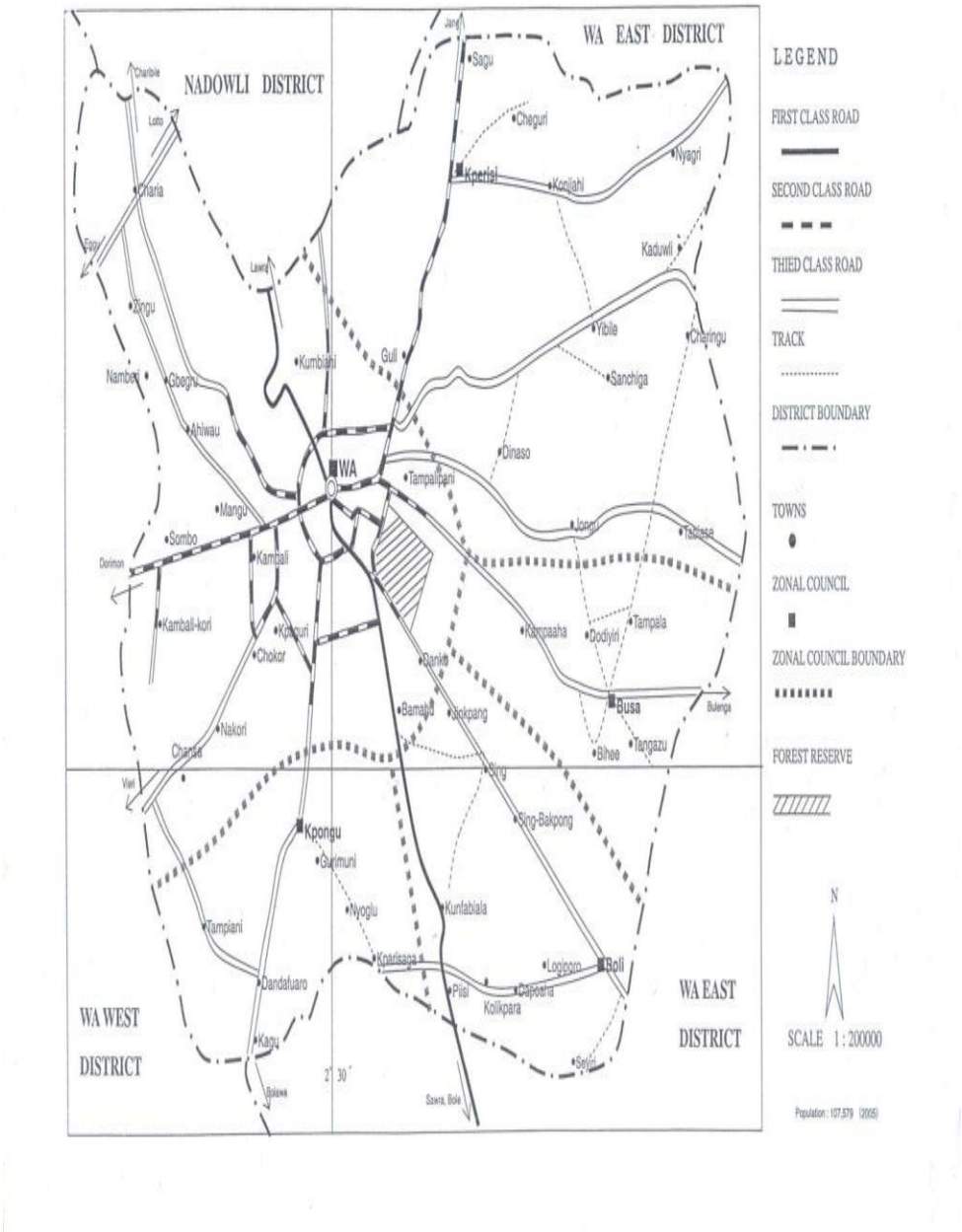


*Figure 3:* A Map of Wa Municipality

Source: Cartographic Unit, Wa Municipal Assembly, 2014

The demographic structure of the Municipality has revealed a preponderance of the dependence over the active working class representing 47% compared to the dependent population of 53%. In terms of educational infrastructure, the study area has 78 Early Childhood Care Development Centres, 76 primary schools, 59 junior high schools, 7 senior high schools, 4 technical/vocational schools, 1 training college, 1 Polytechnic, 1 University campus, 1 teacher training college, 1 nursing training college and 2 special schools (Wa Municipal Education Directorate, 2014). The study area has 20 public and 6 private health facilities with the regional hospital, Wa serving as the only referral facility in the region (Wa Municipal Health Directorate, 2014). Regional hospital, Wa was chosen as the recruitment center because it is a referral center for the whole region where major surgeries like obstetric fistula repairs are mostly done. One major challenge to ensuring quality health care delivery in the study area has to do with inadequate health care personnel particularly doctors (Wa Municipal Health Directorate, 2014). This implies that patients with fistula conditions are more likely to be a constraint in terms of their access to professional medical care.

The main economic activity of Wa Municipality is agriculture employing over 70% of the population (Ghana statistical service-GSS, 2012). This is followed by commerce and industry. Other key sectors of the economy are transport, tourism, communication, and energy. The municipality has about fifteen financial institutions which include both banking and non-banking institutions. However, due to poor financial records keeping, lack of collateral and

high-interest rate, it is difficult for businesses to secure loans from these financial institutions.

**Population**

The study targeted women living with obstetric fistula within the last three years prior to the study. The choice of this category of people is based on the fact that, they were the people living with the condition and as such could best share their experience to achieve the study objectives.

**Inclusion Criteria**

For inclusive criteria, patients who have had the condition within the last three years prior to the study and having sought repaired and patients who have seek repairs and unsuccessful and those who had the repairs and were successful were all considered for the study.

**Exclusion Criteria**

As part of exclusive criteria, non-residents of the Wa Municipality who lives with the condition were not considered for the study. People who were residential and were not Ghanaians were not considered for the study.

**Sampling Procedure**

Two sampling technique were considered for the study. Snowballing and purposive sampling technique was employed to select participants for the study. These techniques were used for identifying information-rich participants who have experienced the phenomenon of interest (Bradley, Curry & Devers, 2007; Creswell, & Clark, 2017). But because women living with obstetric fistula are

hard to come by, snowball method was used to help identify the household in which potential participants are located, purposive sampling technique was then adopted to select the participant for study.

Purposive sampling technique was used to identify women who have been diagnosed with Obstetric fistula. Purposive sampling requires selecting participants who are knowledgeable about the phenomena of interest because they have lived with the condition over a period. This enables the researcher to employ her judgment to select a sample that will provide the needed information. As part of the inclusive, the study utilized women who have been living with Obstetric fistula for the past three years, and willing to participate in the study. The study, however, excluded women who had the condition but lived outside the Wa municipality, as well as women who do not consent to participate in the study.

Participants were visited in their respective comfort zone. The study was first introduced to them, upon consent, they were interviewed. The whole process continues until study got to saturation. A point where no new information is realized from the respondent meanwhile Creswell's (1998) recommendation of 5-25 as a point of saturation was also considered as a guide. Twelve women participated in this study.

**Data Collection Instrument**

The instrument for data collection for this study was a semi-structured in-depth interview (IDI) guide. According to Wilson, Onwuegbuzie and Manning, (2016) the IDI as a tool is flexible, allow for the exploration of emerging themes and ideas. In other words, IDIs provides some scope for asking for more relevant information through additional questions often noted when it prompts the interviewer. It allows the researcher to redirect participants' response when out of context. It also helps the researcher to elicit in-depth information about a phenomenon. Semi-structured in-depth guide gives room to explore people's experiences hence the quest for the instrument.

A total of 12 face -to-face interviews were conducted. The IDI guide consists of four sections. The first section covers the socio-demographic background of participants such as age, occupation, and ethnicity, place of residence, marital status and parity. The second section also seeks to explore participants' experiences living with obstetric fistula. The third section tried to elicit the effect of obstetric fistula one quality of life and lastly coping responses adopted in living with the condition.

**Methodological Rigour**

Rigour or trustworthiness in qualitative research ensures that findings accurately represent exactly what participants intended to say and that findings can be trusted (Lincoln & Guba, 1985). To ensure rigour the criteria of credibility, transferability, dependability and confirmability must be met (Lincoln & Guba, 1985).

Credibility is achieved when the findings from the data reflects reality (Shenton, 2004). In order to ensure this, the researcher purposefully recruited participants who met the inclusion criteria and could give in-depth information on the lived experiences of women with obstetric fistula. Member checks were conducted to verify responses of participants by discussing themes arrived at with them. In addition, each interview was transcribed and coded before the subsequent ones. The researcher requested an independent coder to code some of the transcripts to allow for comparisons to be made.

The second criterion, transferability, is the extent to which the findings of the study can be applicable in other settings (Shenton, 2004). The researcher provided a detailed description of research setting, methodology and background of participants who were used in the study for other researchers to apply when transferring the conclusions of this study to other similar cases. All transcribed data and field notes were kept for audit trail.

Dependability, the third criteria pertains to whether or not the study can be replicated by another researcher (Shenton, 2004). To achieve dependability, the researcher worked with her supervisors from beginning of the research to the end. She provided detailed description of research setting, methodology and background of participants who were used in the study. All participants were interviewed with the same interview guide. Each transcript was subjected to the same method of arriving at themes and sub-themes. A peer researcher was allowed to examine data and this data was also re-coded to ensure accuracy. All documents were also kept for audit trail.

The last criterion, confirmability, is the ability of the researcher to present findings that reflect participants' experiences and not that of the researcher (Shenton, 2004). To achieve confirmability, the researcher sought in-depth experiences of women living with obstetric fistula. The researcher ensured reflexivity by making any biases known or declared. Additionally, observations made during the interview were entered into the field diary. The researcher strived to understand the realities women living with obstetric fistula face. In addition, interviews were transcribed immediately to prevent mixing of information.

To ensure reliability, a graduate student researcher, was allowed to code a selected transcript. Any disparities in the findings were noted and debated until a consensus was reached.

**Data Collection Procedures**

Prior to meeting the women living with an obstetric fistula at the regional hospital Wa, permission was sought from the medical directors of the hospital

who was a specialist in charge of fistula repair in the whole of West Africa who was in the person of Dr. Bananas Naa Gandua. The Principal Nursing Officer (PNO) in-charge of the Maternity Unit of the regional hospital Wa and also the theater in-charge was then contacted for the date scheduled for the visit of the women living with obstetric fistulae to the hospital so that the researcher could meet with them.

At the first meeting, the principal nursing officer-in-charge introduced the researcher to the women living with obstetric fistula and briefed them on the study. The researcher explained the purpose, objectives, and benefits of the study to them using the Participant Information Sheet. After identifying potential participants, detailed information about the study was presented to them individually. Those who willingly accept to be part of the study were made to sign a consent form. The consent form was explained to them in their local dialect after which participants signed or thumb printed consent form before the commencement of the interview. The researcher arranged with each participant the place and time for audio-recorded interviews. The choice of place and time was based on the participant's preference. At every stage of the study, participants were assured of confidentiality by the researcher. The interview was conducted in a language the researcher can speak fluently and understands very well. Saturation was reached by the time the seventh participant was interviewed but five more interviews were done to confirm the emerging themes. The data collected became redundant on the twelveth participant hence twelve (12) participants were used for the study. Data collection continued until data saturation was achieved. Thus

when the same information was heard over and over again, then data saturation was being reached (Saunders, et al, 2018). Hence, when data collection becomes counterproductive where no new evidence is obtained or where new evidence does not significantly change or add to the overall data already obtained, then data saturation would have been reached

Data were collected through in-depth interviews, using open-ended questions. In-depth interviews were conducted one-to-one in a quiet and private place to respect patient confidentiality. The time of the interview was scheduled based on mutual agreement with the participants.

The interview guide covered socio-demographic variables, reproductive history, physical health, and psychosocial lived experiences of women with obstetric fistula. Participants were asked about: their general health condition before having obstetric fistula; their perceptions about why they experienced obstetric fistula; their pregnancy and marital history; their labor and delivery history; their physical health condition following obstetric fistula; and their experiences related to family, husband, relatives and other social groups. Participants psychological feelings and coping strategies were also explored, and participants were probed for additional contextual information about their experiences. All participants agreed to be audio-taped and interviews lasted between 30 and 60min. The in-depth interview guide was prepared first in English and then translated into Waale, and Dagaare, and retranslated back to English to check for consistency by the principal researcher with the assistance of the two-researcher assistance who were master's holders and were experienced in

qualitative studies. The principle researcher has very good control over reading, writing and speaking Waala, Dagaara and English. The two assistance who also had good commend over these languages reviewed the translation.

During the interview, the researcher asked questions, took notes, and recorded participants' non-verbal expressions. At times during the interview, participants smiled, chuckled, and laughed, while at other moments of the conversation they became moody. These were written in the field notes. Field notes were dated for easy correlation with the data. The researcher probed during the interview to focus responses within the objectives of the study and also to get in-depth responses. The researcher listened to the recorded interview a couple of time before transcribing. Each interview was transcribed verbatim and analysed immediately the researcher reaches her office. It took between three (3) to four (4) hours to transcribe each interview. Participants were allowed to validate key issues at the end of each analysed interview often the next day. This was done to ensure the credibility of the findings.

Data collection and analysis occurred simultaneously. All interview transcripts were read multiple times and the preliminary code guide was applied to all transcripts independently. Discrepancies in the application of the coding guide were reviewed and resolved. Following these processes, a final version of the coding guide was developed. This exercise ensured the researcher had a common understanding of the coding guide and its application. The resulting code guide allowed the researcher to capture all major ideas raised by the participants. Coding was done manually. Finally, the codes were sorted into relevant

categories, and the main themes and categories were identified. Significant quotations were clustered into themes and then used to explain participant's experiences and the context that influenced how the participants experienced the phenomenon. The interviews and transcription covered the period of March to May 2019.

**Ethical Considerations**

Ethical approval was obtained from the Institutional Review Board (IRB) of the University of Cape Coast. After that, permission was sought from the Wa Regional and Municipal Health Directorate, as well as the regional hospital to carry out the study in the selected communities, were women living with obstetric fistula were located.

Again, to ensure free informed consent and participation in the recruitment processes, the participant was briefed about the purpose of the studies. Permission was sought from partners (husbands) of the mothers or guidance who granted consent to participate in the studies. This was considered because of the variation in the culture of some people. For example, instances where a woman is supposed to give detail happenings to her husband for him to be aware and to grant approval. Also, before any interview that will take place, participants who were able to read in English was given a written consent form to read and freely decide to participate in the study by signing. On the other hand, those who could not read the informed consent form had it read to them in the language they best understand before participation. Those who consent were asked to thumb-print.

Further, consent was sought from the participant before every interview was tape-recorded. After every interview, the recorded voice and the field notes were stored safely to conform to the ethics of confidentiality. Also, no information that was revealed or identifies names of participants were included in the study report to ensure anonymity.

**Data Management**

Prior to data collection, the date, time and venue of the interview was recorded in a field diary. After each interview, the researcher listened to the audio- recorded interview over and over to familiarise herself with the data and also to know if some additional interview would be needed. Data was transcribed verbatim and stored in a word document. After transcription, a hard copy of each document, audiotapes, field notes, and diaries was locked in a safe cabinet in the researcher's office. The background information was labelled with the same pseudonyms used for the interview and stored safely in the same cabinet. I and only my two supervisors have access to the information. Information will be discarded after five years.

**Data Processing and Analysis**

Thematic analysis was used in analyzing the data collected. This is the process of identifying patterns/themes that are important or interesting and the use of these themes to address the research questions (Braun & Clarke, 2006). Data analysis was carried out in the following sequence. The interviews were conducted in Waala and Dagaare which participant can speak fluently and understands very well and it was translated to English before being transcribed.

The transcription was done by the researcher. She would listen to a sentence, pause the tape recorder, write it down and continue until the whole interview was written down. The main time for transcription of each interview was between 3 hours to 4 hours. As a first step in the analysis, the researcher listened to the audiotapes over repeatedly and transcribed verbatim. This was done by the researcher to familiarize herself with the data. The researcher coded or identified informants' words or phrases and even sentences related and relevant to the area of study. Each transcript was coded separately.

Example: "I am leaking urine and feces", "I feel weak and tired most of the time" The transcript was categorized and identified code was sorted into relevant categories. Example: Leaking/odour, poor body image, transportation challenges, love /intimacy, reduced self-esteem

Finally, the main themes were identified, and the categories were brought together and rearranged under those themes. Examples: Experiences of women living with obstetric fistula, effects of obstetric fistula on participants QOL Significant statements were clustered into themes, forming the "architecture of the findings" and were used to describe what the participants experienced and the context that influenced how the participants experienced the phenomenon. This was the focus on the common experiences, as well as different experiences among the participants (Padgett, 2016). Finally, quotations were used to support the views raised by the participant.

# CHAPTER FOUR

# RESULTS AND DISCUSSION

## Introduction

This chapter seeks to present the discussions and results gathered from participants lived experiences with obstetric in the Wa Municipality in the Upper West Region. The findings from the data were analysed and presented according to the objectives of the study. The four themes that emerged are physical impact, socio-economic impact, psychological impact and coping strategies of women living obstetric fistula. The main themes and their corresponding sub-themes are presented with verbatim quotations. There are four (4) themes and seventeen (17) sub-themes in total.

## Demographic Characteristics of Participants

Participant's age ranges from 21 to 49 years (see Table: 1 below). Majority of the participant were in their 40's with few of them found within the '30s and '20s. More than 50% of them were leaving with mothers after they developed and a significant portion of them staying with their husband. Many of them on another hand were unemployed and have divorce as their marital status. As seen in table 1.

**Table 1: Demographic Characteristics of Participants**

| No. | Participant | Who participant lives with | Age | Occupation | Marital status | Parity |
|---|---|---|---|---|---|---|
| | (pseudonym) | | | | | |
| 1 | P1 | Mother | 40yrs | Unemployed | Divorced | G2P2(One alive) |
| 2 | P2 | Husband | 42yrs | Farming | Widow | G4P4(One alive) |
| 3 | P3 | Mother | 38yrs | Farming | Widow | G5P5(One alive) |
| 4 | P4 | Husband | 46yrs | Farming | Married | G6P6(Three alive) |
| 5 | P5 | Daughter | 45yrs | Unemployed | Divorce | G10P10(Three alive) |
| 6 | P6 | Stepmother | 47yrs | Unemployed | Divorce | G5P5 (Two alive) |
| 7 | P7 | Husband | 35yrs | Farming | Married | G2P0 (All dead) |
| 8 | P8 | Mother | 38yrs | Unemployed | Divorce | G1P1(one dead) |
| 9 | P9 | Mother | 21yrs | Unemployed | Separated | G2P2(All alive) |
| 10 | P10 | Husband | 44yrs | Unemployed | Married | G8P8 (Three alive) |
| 11 | P11 | Mother | 49yrs | Unemployed | Divorce | G7P7 (Four alive) |
| 12 | P12 | Mother | 21yrs | Farming | Divorce | G1P1 (one dead) |

Source: Fieldwork, (2019)

**Table 2: Thematic framework of the finding**

| Objectives | Themes | Sub-themes: |
|---|---|---|
| Experiences of women living with obstetric fistula | Physical impact | Leakage and odour |
| | | Poor body image |
| | | Genital sore |
| | | Foot drops (partial paralysis) |
| | Socio-economic impact | |
| | | Social Life |
| | | Religious activities |
| | | Transport challenges |
| | | Love and intimacy |
| | | Divorce |
| Effect of obstetric fistula on participant quality of life | Psychological impact | |
| | | Reduced self-esteem |
| | | Anxiety regarding treatment |
| | | Stigmatization |
| | | Hopelessness |
| Coping strategies of women with obstetric fistula | Coping Strategies | Personal Hygiene (Use of perfumery and diapers) |
| | | Isolation |

Source: Fieldwork, (2019)

**Experiences of women living with obstetric fistula**

In relation to the research question "what are the experiences of women living with obstetric fistula". Two themes emerged namely; physical and socio-economic impact of obstetric fistula. Several sub-themes however emerged under these two. Under Physical impact, sub-themes that emerged were**;** leakage /odour, loss of appetite leading to poor body image, genital sore, and foot drop/partial

paralysis. Under the Socio-economic impact sub-category; social life, reduced ADL, religious activities, transport, love and intimacy/divorce and financial constraints emerged as subthemes. The participant's experiences were generally alarming due to the untold suffering characterized by pain, shame, and societal stigmatisation. All these elements as expressed in their responses cut across all four themes and also presented below.

**Leakage and Odour**

Many of the participants in their quest to share the experiences they have living with fistula. A number of them attested that leakage and odour was one of the striking experiences they have to live with. This was what some of them have to share:

> *"The smell from the urine and faeces is unbearable to even me, how much more to talk of others "People shun my company. As for friends, I don't have friends any longer. I have been sacked from gathering on several occasions. With this stench emanating from me, who will agree to come and sit with me inhaling it, when I am in the midst of people, some of them behave to show that they are uncomfortable with my presence such as holding their noses. This is very demeaning as it signifies that they cannot stand the stench from me. Because of this, I have become useless and can no longer be among peers." P1.*

A participant added with tears dropping from her eyes:

> *"Hmmm my sister you know the smell of urine is more offensive than even faeces so, my heart usually bleeds when I hear of funerals and marriage ceremonies, not because of anything but the stigma. As soon as people see you, they begin to point fingers and others holding their nose and will openly tell you that you smell of urine so you cannot sit with them. So, I usually go to the funerals of very close relatives. I don't usually stay for long; I leave there as soon I greet them" P2*

Another participant also added:

> *"When I am in the midst of people, some of them behave to show that they are uncomfortable with my presence such as holding their noses. This is very demeaning as it signifies that they cannot stand the stench from me" P3*

**Loss of Appetite**

Loss of appetite was one of the major sub-theme that emerged under the physical impact subcategory. It resulted from the participant's not eating and drinking for the fear of leaking urine and faeces were ever they go. Accounts from the study revealed that most of the participant experience loss of appetite/ thirst which also leads to poor body image due to weight loss. Most of them had this to share:

The participant could not eat or drink for the fear of leaking urine and faeces

> *"hmmm, I cannot go out in public without a diaper on, because immediately I drink water, urine will start leaking on me" P8*

Another participant lamented in a low tone

> *"The fear of walking with urine dripping prevents me from even drinking water" P5*

Other participants attributed their poor body image to loss of appetite

> *"First, I was not thin like this; I was a fat person. But look at me today. This is because I cannot eat or drink adequately." P4*

**Genital sore**

It was also observed that almost all the participants reported suffering some degree of physical health problems such as genital sore and foot drop (partial paralysis). The genital sores were due to irritation of the skin around the genital area by the constant contact with urine. Participants experienced a foot drop. The following narratives summarize participants' experiences:

> *"The frequent pouring of urine irritates my skin and causes sores on my genital area. The pain is so much that I cannot use the rag as a pad because when I walk and my thigh rub one another it is usually very painful. So, I just hang any cloth on myself to cover my nakedness"* P6

*"Hmmm you know urine is acidic in nature and when am always soaked with it causes irritation on my genital area. When I scratch, I get sores and it unbearable" P7*

**Foot drops (partial paralysis)**

A frequent complication associated with the obstetric fistula was perceived paralysis particularly of the lower limbs, which led to foot-dragging, making the women even more outcasts and making it even more difficult for them to access care. Participants' responses included the following

*"I went to the village to see my mother, that was where the labour started and I spent a whole night in their clinic before they brought me to Wa regional hospital. I was operated on the following day in Wa. It took me about one month before I could walk after the operation" P2*

*"I had just finish taken my supper and the labour pain started. I was in pain till the next morning, in three days I was in labour. I could not get transport from my village to the hospital immediately the pain started. The car got spoiled and I had to wait for them to repair the car before I could get to the hospital. It took them three days before they could get a means of transport. Moreover, because of the labour pains, I couldn't sit on the motorbike. I had to wait for them to repair the car. It was the car that delayed my movement to the hospital. As soon as I got to the hospital, I was arranged for the*

*theatre and the child was removed. I also became paralyzed. And I ended up with this condition" P3*

**Socio-Economic Impact**

Socio-economic impact is another major sub-category that emerged under the main the theme 'experiences of women living with obstetric fistula'. Sub-themes that emerged included; social life, reduced ADL, religious activities, transport, love and intimacy/divorce, and financial constraints. Most of the participants reported getting scornful remarks from associates and other people. The majority also reported isolation, abandonment, rejection, dejection is shunned by loved ones and family members. They suffered all these in addition to the loss of baby and loss of a job. This continually resulted in social isolation and self-ostracism among the participants. These issues impacted greatly on affected women's lives in that their abilities to continue to do things that they previously did was affected. Most participants reported that they are unable to participate in religious and community activities and even when they cook nobody eats their food or drink their water, even their own parent. Majority of the participants were not able to mingle with people and cannot use public transport due to the negative reaction from people.

**Social Life**

Issues of social life were also pointed out as socio-economic experiences faced by participants. Some of the participant attested to the fact, they are finding

life very challenging couple with the condition. Below were some of their testimonies shared;

> *"I don't have any job ever since 1 developed this condition. I used to brew pito and prepare koose and sell in the market but as you know a lot of people shun your company because of the persistent smell of urine perceived from you, I now depend on people for my survival" P6*

Other participants added:

> *"No one cares about me I use to brew pito and manufacturing of share butter but because of the condition, I don't do any of that. I now do go to the farm during the raining season. Since am always alone at the farm, nobody will say urine and faeces smell here" P2*
>
> *"I cannot mix with friends and other women anymore, and I can't work but only sit in one place. I cannot be like my fellow women again nor be able to play my role effectively as a woman; this is a very difficult and pathetic situation to bear I preferred my death to live" P8*

With tears dropping another participant had this to share;

> *"I was always thinking about how a living being can live without mixing with people. When I sit with people, I get wet, when I walk past people they hold their nostrils due to my smell I was always thinking about how God could do this to me. I can no longer go to the market to sell and cannot do anything again" P4*

Others also mentioned

> *"I am always washing my cloth I felt ashamed mingling with people. As soon as I get to gathering you see people pointing fingers at me, and when you sit by them, you see them getting up one by one and others will openly hold their nose and say hmmm urine and faeces are smelling hear. When I cook nobody eats. I am always worried because when I go to a funeral you see people looking at me in strange manner. Am not always able to walk." P4*

**Religious activities**

Most participants reported that they are unable to participate in religious and community activities and even when they cook nobody eats their food or drink their water, even their parent. According to a number of them, their faith has been reduced to total isolation and stigmatization.

Participant stated

> *"I feel being isolated and abandoned by my family and community members. Nobody want to associate with me anymore. Am shunned by those whom I have known in my whole life. I feel dejected and rejected. I am not able to participate in religious practices such as going to the mosque to pray. I was the; makaazia;(women's group leader) in my community, but now I have been prevented from participating in their activity because of my condition" P8*

**Love and Intimacy**

Love and intimacy refer to a close personal relationship of women living with obstetric fistula with significant others or the ability of women living with obstetric fistula to be very strongly attracted to some in an emotional and sexually way. However, in this study participants reported they have a lack of affection and intimacy ever since they had the condition. Majority of the women reported they do not have sex with their husbands ever since they developed the obstetric fistula. They are not happy about their sexual life. Many expressed bitter experiences such as neglect/abandonment.

Participants express their experience this way;

> *"I was no longer staying with my husband in the same room. He abandoned me and was chasing a different girl. He even some times brings the women to our matrimonial home. Am not happy but what can I do. No sex at all" P9*

However, some of the participants also reported that they still experience love and intimacy with their husbands;

> *"I was and am still his only wife. Our sex life has not changed despite my condition" P4*
>
> *"We do have sex and give birth to children but you know, it cannot be as someone without any condition. When you are like that, you cannot pair a bed with your husband. He only comes to your room as and when he wants to have sex with you" P7*

*"We do have sex. My father added my sister as a wife to my husband because of the condition" P10*

**Divorce**

Divorce was among one of the major issues reported which resulted in stress and upheaval in these women. Amato (2010) defined divorce as a decision to leave a partnership and the ending of a marriage. In the present study, participants expressed their views regarding how fistula has affected their relationship with their husbands or partners. Some of them recounted with pain how they were abandoned by their married partners without social and financial support

Some participants reported

*"I was abandoned by my husband. He drove me out immediately and married another woman." P1*

Another mother lamented that:

*"Due to the condition, we don't have sex anymore. My life has changed drastically and I think is because of the condition" P3*

Others, however, reported that the condition did not affect their marital/sexual life in any way

*"I was and am still his only wife. Our sex life has not changed despite my condition." P4*

*"My sexual relationship with my husband has not changed "P10*

**Transportation challenge**

Transportation was also pronounced by respondents as one of the challenges are they confronted with living this condition. This experience they are confronted with aggravating in different forms most especially when they want to travel. Many lamented and said because of the publication reaction to them when they decide to, they are usually sacked indoor. Participants have this to share:

> *"I use to buy food staff and send to Wa to sell but I cannot do that anymore, due to the smell of the urine am not able to use public transport. I use to hide and still go to Wa market until one day a driver and some passengers told me openly I smell. And even nobody will go to sit by you, so I had to stop the work" P7*

**Psychological Impact**

In relation to the research question "How do their lived experiences affect their quality of life?" Psychological impact was a major theme that emerges as key thematic issues affecting their wellbeing as they live with the condition. The sub-themes that emerge include; Reduction in once self-esteem, Anxiety regarding treatment, divorce, and stigmatisation.

**Self-esteem**

The participant reported their self-esteem has been reduced and because of that, they feel hopeless. A majority reported the fistula makes them think so much to the extent that it disturbs participant emotionally. This emotional disturbance makes them not to be able to sleep

> *"I am always thinking, and this has made me not to be able to sleep because I was not like this and now I have lost not only my health but also my long-awaited baby boy. I call him my long-awaited boy because I have been married for the past ten years without a child. In the night I cannot sleep due to this condition Periodically I have to leave whatever I am doing to go change my soiled clothes to prevent embarrassment. This has made me feel hopeless and worthless. Oh, death where are you? Come and take me." P1*

Another participant also lamented that;

> *"I lost not only my health but also my child. The taught of this worries me so much. I feel pathetic and dirty, and am always thinking." P2*

**Hopelessness**

Women living with OBF experienced a feeling of despair, dejection and a lack of confidence for the future. Majority of these women experienced a feeling of hopelessness. They had this to share Participant mentioned

> *"I thought death was better and I wished for death. It is a shameful disease and as a result, I see myself as useless. Some people think I went and looked for the sickness I was worthless due to the condition. I felt like I am not a full human being. The disease is a very bad disease and as a result, people don't respect you again. When I sit with people and someone urinates close by and*

*the smell felt around where we sit everyone always thinks it is me" P9*

**Anxiety regarding treatment**

Most of the participant reported that they feel anxious regarding treatment as to whether they will ever be well again. This is because they have had repairs for about two to three times yet they still live with it.

Most of the participant expresses their worry as stated below;

*"I have undergone surgery once but it was not successful. I am still living it. I have undergone repairs twice but it was not successful. I am still living it. The faece stopped pouring but my urine still pours and I don't know whether I will get heal or not" P12.*

*"I use to think, I was worthless because I could not do what I use to do. I am always thinking whether this disease can ever be treated or it will be like this throughout my life. I can no longer pray" P6.*

Another participant reported

*'The condition keeps me thinking and even sometimes when I get food, I can't eat. I wonder if I will ever get treatment." P5*

*"I lost not only my health but also my child. I see that as a double punishment. I also faced rejection from my husband. Ahaaa will I ever be well again hmmm" P8*

**Stigmatisation**

Similarly, stigma contributes to the embarrassment that these women feel when seeking healthcare. Like the nurses, the physicians' interviews here also identified accusations of witchcraft as one of the potential reasons why women do not seek treatment: at certain circumstances, the stigmatising nature of obstetric fistula compounds by traumatic experiences like insults from the community and family members made their lives more challenging. In addition, they had "a feeling of being inferior, sinful, and shamefully different, and losing hopes on the future". Participants have this to share:

> "*My friends have shunned and abandoned. My best friend whom I use to eat and share my secrete with do not want to come close to me for the fear that she will be stigmatised" P11*
>
> *"Some of my family members sympathise with me because sickness is from God, but others insult me. Sometimes they insult my children, they laugh and make fun of me, it disturbs me, but I cannot do anything about it so to avoid this humiliation, I stay away from people" P12*
>
> *"My friends and family act like they are fed-up with me. They no longer value me. When I go close to them, they usually sack me. I was assisted to get a job by someone upon getting there the bar owner asks me to start to work the next day only for me to get there the next day and she said I smell urine and if she does not sack me her customer will stop eating from her. So she asked me to go" P9*

**Coping Strategies**

Participants shared out two most important coping strategies they adopted when confronted with public stigma and when they frequent pour out. These key strategies include; personal hygiene (Use of perfumery and diapers) and isolation.

**Personal Hygiene (Use of perfumery and diapers)**

Participants utilized various constructive strategies and resources to reorganise their daily lives based on the nature of the event they experienced and the resources they had. This involved seeking family support, selling their property, and orientating to reality. Almost all the participant adopted frequent bath and washing of cloth and rags and the use of diapers.

> *"I clean myself and wash my cloth and rag (old cloth) frequently. Hmmm, I cannot even tell the number of times I wash in a day. Moreover, when I get money, I buy perfume and adult diaper and use." P2*

> *"I wash myself and my clothes frequently. My people use to support me and encourage me and that even has minimized my thinking" P5*

> *"I do use rags as pad whenever I am going out or going to farm. I also wash the rags most often as soon as the rags are soiled. When I do go for prayers, it also comforts me because when I listen to the bible it is comforting" R6*

**Isolation**

Self-isolation was one of the emotion-focused coping strategies developed by the participant. Some of the women reported that their friends, neighbors, or relatives had invited them to social events, but none wanted to accept these invitations. They preferred to withdraw from social activity and spent most of their time alone. This was because they were afraid of leaking urine and its smell, depression, and feeling anger and shame when they saw their friends.

> *"I do tell my brother to plough an acre for me. When I wake up in the morning, I start moving to the farm and when I am there, I do not worry about anybody or anything. I wash my rags always" P7*

> *"I use to take rags as pad to absorb the urine and without that, I cannot go anywhere my relatives use to sympathies with me and that also kept me going. When we were asked to come to Wa, that was the day I went and met a bus of people and I was told they were all having that same condition. I did not even get space to enter the bus that day but that was the day I slept very well because I now know I am not the only person with the disease. This full bus and they said they have all had treatment, which means one day I will also be treated. I isolate myself from people by making a garden at the valley (pointing) I go and spend the whole day there all alone." P10*

**Discussion**

The main purpose of this study is to explore the lived experience of women with obstetric fistula in the Wa Municipality. This discussion covered the patient's experiences, determinants that compromise their quality of life and coping strategies they adopt in addressing this canker. Baker and Intagliata (1982) model on quality of life (QOL) was adapted to guide the entire study. This model was considered because it consists of domains which was suitable for generating the appropriate information to meet the objectives of the study.

The quality of life of women living with obstetric fistula in the framework answers the first objective which seeks to examine how the disease condition affects participants wellbeing in terms of physical, socioeconomic, physiological and culture.

Health problems that may arise could be a disease-specific effect of physical wellbeing such as discharge of urine/faeces, body odour, and fitness. The socioeconomic involves the interaction of the women living with obstetric fistula with others. The parameters under the socioeconomic are social and economic activities, such as isolation, inability to work, divorce and stigmatization. The psychological refers to the emotional functioning of the women with obstetric fistula example low self-esteem, low sense of purpose, depression, and anxiety. Culture refers to the participant personal beliefs and attitudes

The lived experience of women with fistula refers to Life conditions and events as they are perceived by the patient. Women living with obstetric fistula may experience material challenges such as housing, nutrition, financial and

transportation as well as social and religious interactions. These lived experiences can be influenced by the dimensions of quality of life in the framework which includes physical, socioeconomic psychological and cultural.

The last construct on the framework which was coping strategies measures the third objective of this study which describes the coping strategies of women living with obstetric fistula. This is conceptualized from the point of view that, the patient lived experiences influenced her coping strategies. On the other hand, whether the coping strategies are positive or negative, they will also intend to influence the participant quality of life.

**Experiences of Women Living with Obstetric Fistula**

This study found that experiences related to the personal happiness of women with fistula are that of sorrow and sadness. The severity of their sorrowful life manifested in their expressions. Four themes that emerged from the analysis of the IDI are interlinked and women look at themselves in the context of a social environment as a woman with specific roles not fully fulfilled but also devise strategies to cope. The women perceived leaking urine and odour to be discrediting, felt different from other women and were isolated from the rest of society. These findings are like what has been reported in other low-income settings in Africa and Asia, with the general agreement that a fistula has negative social and psychological implications that result from its physical manifestations (Wallet et al, 2004, Bangser et al., 2011, Roush, 2009, Dahlgren, Emmelin, & Winkvist, 2004, Mwini-Nyaledzigbor et al., (2013). The findings show that urinary incontinence following fistula impacts on several aspects of the affected

woman's life including physical, psychosocial and economic wellbeing, as has been reported elsewhere (Hayder & Schnepp, 2010). Like what was earlier reported in Nigeria (Wall et al, 2004), the findings of this study show that the worst suffering is not from the physical manifestations of the fistula, but rather from the social, psychological and sexual impact the condition which usually results in many patients to develop poor body image in the eyes of people. Poor body image has also been established in literature has a bad image experience by fistula. This finding is consistent with the conceptual framework that denotes that psychological factor such as poor body image interplay with social interaction and causes persons living with OBF view herself as lifeless.

The findings of this study is consistent with previous research in rural Ethiopia (Muleta, 2004; Muleta et al., 2007), Eritrea (Turan, Johnson & Polan, 2007), Nigeria (Kabir et al., 2004), regarding the physical problems experienced by women who develop obstetric fistula. The physical problems described by the participants, including Genital sore, skin irritation and rashes in the genital area, offensive odour, pain, urinary tract infections. Studies (Mwini-Nyaledzigbor, Agana & Pilkington, 2013) also reported that unpleasant smell of urine, the stigma experienced by the participants was tied to people's beliefs about prolonged labor and fistula being the result of a woman's misdeeds. This "blame the victim" response was also noted by Wall (2006, p. 1205)

The study further reveals that some patients of fistula experience Foot drop. This finding is consistent with previous reports by Kimani *et al.*, (2014) and fistula foundation (2019) which revealed that some women with obstetric fistula

suffer from “foot drop,” which is the inability to walk properly without help, due to injury to the common fibular and sciatic nerves caused by prolonged labour. Similarly, participant in our study revealed that women who develop obstetric fistula suffer nerve injuries that can cause foot drop and long-term walking impairment. Participant acknowledged that women with obstetric fistula can develop foot drop; but, among the interviewed women who lived with obstetric fistula, majority reported that, they did not experience nerve injury or foot drop

**Effect of Obstetric Fistula on Participant Quality of Life**

Psychological effects were also unearthed by the study as some of the possible consequence fistula patients in the various localities are confronted with a burden in the daily dealing. These consequences as revealed include stigmatisation, divorce, reduced self-esteem and Anxiety regarding treatment. The concept of stigma has been extensively discussed in the literature. According to Goffman, (1963) Stigma is defined as an attribute that is deeply discrediting and that which reduces the woman from a whole and normal person to a tainted or discounted one. Stigma was observed in three forms in this study: internal, external and caregiver. One type, internal stigma, occurs intra-personally when the stigmatised individual internalizes the negative stereotype; for example, the woman living with Obstetric fistula may tell herself, I am worthless; I am unclean (Link & Phelan, 2001). External (interpersonal) stigma is when the stigmatised individual is treated differently during social interaction because of a negative stereotype. Caregiver (interpersonal) when family members or other caregivers experience external stigma because of their relationship with a stigmatized

individual. Another study found that stigma against women with fistula manifested itself in various ways. This ranges from subtle to blatant discrimination and isolation. The stigma continues even after corrective surgery. The study further revealed that stigma was by their families and the community. These findings are also consistent with Watt et al., (2015), Wilson, (2015) and Rahm, Renck and Ringsberg, (2013) also pointed to the fact that women with obstetric fistula are socially stigmatised and marginalised, psychologically affected and economically deprived, and often suffer a traumatic birth experience. These situations are correlated with mental health problems (Kuo, Chen, &Tzeng, 2014). Obstetric fistula associated with mental health problems is one of the most burdensome diseases among women in their early productive years. Studies in low-income countries, including Ethiopia, report that women with fistula have a significantly higher incidence of symptoms of depression, psychosocial dysfunction, and anxiety (Dennis et al., 2016). Clearly, there was much resentment, rejection, and disapproval of women with obstetric fistula. As such, it is like certain other illnesses and behaviors (e.g., mental illness, leprosy, tuberculosis, sexually transmitted diseases, HIV/AIDS, prostitution) that are considered disgraceful, and, thus, stigmatised, in Ghanaian society (Mwinituo & Mill, 2006).

Divorce was also revealed as one of the consequences affecting many women living with obstetric fistula because of their state of being. Usually, these women are abandoned by their husbands and partners and their people. These experiences were common among many women with fistulae. Others, due to the

onset of obstetric fistula, some husbands divorce their wives because of bad odour and leakage of the urine that is disgusting to them. Others divorce their wives because obstetric fistula survivors cannot satisfy them sexually while others divorce because the obstetric fistula women cannot produce other children in the future, and it may take them years to recover. This finding is consistent with Yeakey, Chipeta, Taulo and Tsui, (2009), findings that indicate that the experiences of Malawian women with fistula were found to have high rates of divorce and stigma. Many women, in addition to their families, discussed high levels of support from those individuals closest to them. Nonetheless, many women experienced the fistula as a direct assault on their ability to fulfil social expectations of them as women, wives, and mothers. Women identified fertility and continued childbearing as central concerns

The study added that reduced self-esteem and Anxiety regarding treatment were some of the striking effects lashed by these women at the participant locality. These finding consequently adds to the revelation Pope, Ganesh, Chalamanda, Nundwe & Wilkinson, (2018) who posit that fistula as a condition is also associated with psychosocial problems such as depression and anxiety, which may further contribute to the inability to seek treatment due to that anxiety one builds within herself. On the other hand, the microsystem therefore as spelt out by the ecological system model by Bronfenbrenner (1979) also show the relationships and interactions patient has with her immediate surroundings (Araujo, Davids & Hristovski, 2006). Once the patient lacks that social networks and social support systems that can influence individual experience, including

family, spouse, friends, peers, religious networks, customs or traditions, their resistance to seeking treatment will reduce and increases when the inverse exist.

**Coping Strategies of Women with Obstetric Fistula**

Based on the social stigma theory according to Goffman, (2009), both enacted and perceived (felt) stigma, are weaved into the lived experiences of women with a fistula, making them feel alone and isolated. While trying to maintain mental and emotional wellbeing, the women devised ways to cope with the challenge of leaking urine, though some of the coping strategies turned into stressors that often lead to even greater stigma. The women's lives, while living with fistula, revolved around ways to prevent the leakage of urine or faeces being noticed and reduced the smell. Amidst all these life adjustments to cope with the consequences of the fistula, these women found themselves lonely and isolated.

The study also reveals that, one reliable means which the women living with obstetric fistula adopt in managing the condition is maintaining their daily personal hygiene (frequent washing of oneself and cloth, use of perfumery and diapers). This finding is consistent with Plummer (2001) Labeling theory which posit that to avoid the social rejection, stigma, and discrimination arising from being a woman with a fistula, the participants did not reintegrate into their family and local community what they usually adhere to is isolation. In a similar vein, Plummer described how social responses, including stigmas and labelling, have their own effects on social behavior and personal identity. This is because the person takes on the label. Analogous to Plumbmer, (2001), Morse (2000), also

found that once people have suffered enough and are able to accept their changed reality, they gain new insight and appreciation of life and their changed reality.

The study findings contradict to the findings shared by WHO, (2006) report. Per the report, some coping mechanisms cited by women as they experience socially unaccepted condition fistula includes isolating themselves by staying home, keeping their fistula a secret, working, being supported by the family, praying and reading the bible, and perseverance/self-determination. Empirical studies have also acknowledged other studies in discussing this phenomenon. For instance, the study by Wall, (2006) also attested that Despite abandonment and neglect by spouses and family members, family was still the most reliable source of social support for the participants in this study. He argued that, supports such as provision for basic needs such as food, detergents, and clothes, assistance with personal hygiene, and accompanying the women to the hospital for treatment. Spousal and family support may be withdrawn, however, when it becomes apparent that the women's condition is chronic.

Seek for care in a form of repair has also been established in literature as one of the copping strategies adopted by most fistula patients. Wang et al. (2014) in China in conjunction care seeking as an alternative to mute the condition, reveals that women with moderate internalised shame (stigma) have stronger intentions to seek care than those with low or high levels of internalised shame.

# CHAPTER FIVE

# SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

## Introduction

This chapter presents the summary of the study, implications of the study to nursing practice, education, research and management, conclusions and recommendations of the study. It first summarizes the entire work and then presents the key findings of the study. The chapter also captures conclusions and recommendations of the study.

## Summary of the Study

A phenomenological study design was employed to explore the lived experience of women with obstetric fistula in the Wa Municipality. Specifically, the study strives to describe the lived experiences of women with Obstetric fistula, how obstetric fistula affects their quality of life lastly their coping strategies living with obstetric fistula. The study was carried out in the Wa Municipality. The Municipality had six sub-districts with functioning CHPS zones in each sub-district. Out of the six sub-districts, six completed CHPS zones were included in the study. An in-depth interview guide was the main instrument used to elicit the information from key respondents. In all, twelve (12) IDIs were conducted. Thematic analysis was used in analyzing the data collected.

**Findings from the Study**

The participants' ages ranged from 21 to 49 years. Majority of them were in their 40's with few of them found within the '30s and '20s. More than 50% of them were leaving with mothers after they developed the fistula and a significant portion of them staying with their husband. Many of them on another hand were unemployed and have divorced.

The study reveals that Physical impact (Leakage and odour, poor body image genital sore, foot drops (partial paralysis) and Socio-economic impact (Social Life, religion activities, transport challenges, love and intimacy) were some of the experiences women living with obstetric fistula had.

It was also discovered that psychological constituting reduced self-esteem, Anxiety regarding treatment, Stigmatisation and Divorce were unearthed as various effect confronted with by obstetric fistula on participant quality of life. Based on the experience and effects confronted with by participants, a number of coping strategies were recommended by these participants as means they adopt to daily confronted issue namely; personal hygiene that is the usage of perfumery and diapers) and Isolation approaches.

**Implications of Findings**

The findings of the study presents implications for, nursing practice, nursing education, and nursing administration.

**Nursing practice**

Nurses play a significant role in the delivery of obstetric services. The findings of this study suggest that the quality of life of a woman living with obstetric fistula depends on the education given her on how to manage the condition. This points to a gap in health education particularly of women and families in rural areas. Nurses can fill this gap by intensifying education about obstetric health to women. Also the attitude of nurses towards women seeking obstetric health should be cordial, welcoming and loving to encourage women to make the health care setting their first contact for obstetric services. Women living with obstetric fistulas should be given the needed care and professional supports from nurses to enable them feel comfortable worthy and confident of their human dignity.

More nurses should be trained as specialists in giving obstetric care services to enable them give efficient care to women seeking obstetric services. Participant's responses revealed that most of their experiences were centered on the QOL model by Barker and Intagliata (1982). Therefore, nurses should consider using items in the framework to care for women living with obstetric fistula

**Nursing / public education**

A comprehensive obstetric care of women should be included in the curricula of the Nursing and Midwifery. Also, in service and regular training should be organize for midwifes and public health nurses to enable them upgrade their knowledge on managing women during pregnancy, labour and delivery.

**Nursing administration**

Nurses and midwifes are core stakeholders in the fight against obstetric fistula. Incidence of obstetric fistula should be monitored by nurse administrators and public health offices to determine the scope of the problem. Nurse administrators should conduct an evaluation and follow up services in places where obstetric care policies have been implemented. This will help to determine the effect of the policies on the health of women who receive the services rendered.

**Conclusion**

The quality of life of persons living with obstetric fistula is affected drastically. Even though obstetric fistula is preventable, most rural women are being affected by this condition. This study revealed that obstetric fistula has physical, socioeconomic and psychological impact on participant's quality of life and the coping strategies they adopt. Participants reported that they have been stigmatized and shunned away by loved ones. Support in the form of financial and emotional offered by their family was what helped women living with obstetric fistula to cope with the adaptation process. Findings also reveal that a good adaptation to a large extent depended on the quality of education offered by the health team. Though the participants acknowledged the work done by the nurse, they wished more was done in terms of their education.

This study has provided a deeper understanding of the lived experiences of women living with obstetric fistula. It is therefore hope that this understanding will better place health care delivery to benefit persons living with this condition

and inspire nurses to be mindful of how they themselves can significantly influence their patients' experience with obstetric fistula.

**Recommendation**

With reference to the findings of this study, the following recommendations have been made to women living with obstetric fistula, nurses who care for women living with obstetric fistula, the regional hospital Wa, and the Ministry of Health

**Women living with obstetric fistula**

There should be a concerted effort on the part of women living with obstetric fistula and other stakeholders to form support groups to help them share feelings, problems and ask questions that bother them.

**Nurses**

1. Health education and counselling sessions should be given to families with women living with obstetric fistulas to enable them to accept and support the women living with obstetric fistula to enhance their quality of life
2. During antenatal visits or contacts. Women should be screened to identify those who are at risk early and help them plan their delivery or labour.
3. The Ghana Health Service Directorate or Public Health Directorate in the Region should liaise with the religious groups in town to form a social support group for these women since the study indicated a strong reliance on religion for coping.

**Regional Hospital, Wa**

1. In-service and regular training should be organized for midwives and public health nurses to enable them to upgrade their knowledge of managing women during pregnancy, labour, and delivery.
2. The hospital in collaboration with other stakeholders should endeavour to advocate and form support groups. Reintegration efforts should be instituted to reduce the emotional and economic impacts of fistula on victims through the establishment of fistula support, counselling centers and associations for victims to identify themselves with as well as the provision of food aid.
3. A comprehensive education campaign should be launched by the public health unit to educate residents of the Wa municipal on Obstetric fistula

**Ministry of Health**

1. For those who live with the fistula, more treatment centers should be developed especially in the rural and economically disadvantaged areas to improve accessibility to treatment
2. The Ministry of Health should endeavour to have the cost of the obstetric fistula repairs covered by the National Health Insurance Scheme.
3. Policy document on management of obstetric fistulas should be formulated and implemented.

**Suggestion for Further Studies**

The experiences of men who have wives with fistula and still remain remarried to them should be explored to find out why they stayed with them and

the implications. Further researchers should be conducted on the needs of women living with obstetric fistula.

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# APENDICES

## APPENDIX A

## INFORMED CONSENT FORM

**TITLE: LIVED EXPERIENCE OF PEOPLE WITH FISTULA IN THE WA MUNICIPALITY**

Principal Investigator: *Sufuyani Gladys*

Address: school of nursing and midwifery, cape coast UCC

**General Information about Research**

I will like to seek information about your experiences of living with obstetric fistula. The information that will be given by you will help others to understand the challenges people who have obstetric fistula face and how they cope. I will have a conversation with you in Waali, Dagaare or English which will last between forty-five to sixty minutes. There is no right or wrong answer and you will not be judged for your answers therefore you should be comfortable in answering any question asked you. You will be asked to sign an informed consent form before the interview begins. The interview will be audio taped with your full permission.

**Procedures**

You are being invited to take part in this interview because we feel that your experience as a person living with obstetric fistula can contribute much in determining the challenges, how it affect your quality of life and the coping strategies you have. If you accept, you will be required to participate in an interview with myself. If you do not wish to answer any of the questions posed during the interview,

you may say so and the interviewer will move on to the next question. The interview will take place at a place convenient to you and no one else but the interviewer will be present. The information recorded is considered confidential, and no one else except the researcher and her supervisors will have access to the information documented during your interview. The expected duration of the interview is about 45-60 minutes

**Possible Risks and Discomforts**

There is no direct physical harm if you take part in this study. Though, you may not be comfortable talking about your experiences. However, in the course of the interview if anything happens the interview will be stopped, you will be reassured and made calm whiles an expert from the Regional hospital, Wa counselling unit will be invited to give you a free counselling session.

**Possible Benefits**

By doing this study, nurses and other people will know more about the condition so that measures can be taken to improve upon obstetric care as well as prevent future occurrence of the condition.

**Confidentiality**

Although the interview will be audio taped, your name will be replacing with synonym and any other information that will identify you will be deleted. However, you will be given a code number or a coined name that will be attached to the information you give during the interview. Only my supervisors will have access to the information.

**Compensation**

You will not receive any compensation.

**Voluntary Participation and Right to Leave the Research**

Your participation in this study is voluntary and therefore, you have the right to withdraw at any point during the interview without any explanation

**Contacts for Additional Information**

Sufuyani Gladys

Phone number: 0243109991

Email: g.sufuyani@gmail.com

Dr. Jerry Paul Ninnoni

School of Nursing, University of Cape Coast

Phone number: 0503280047

Email: jerry.ninnoni@ucc.edu.gh

Dr. Mrs. Evelyn Asamoah Ampofo

School of Nursing, University of Cape Coast

Phone number: 0208131658

Email: evelyn.ampofo@ucc.edu.gh

**Your rights as a Participant**

This research has been reviewed and approved by the Institutional Review Board of University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00 am and 4:30 p.m. through the phones lines 0558093143/0508878309/0244207814 or email address: irb@ucc.edu.gh.

**VOLUNTEER AGREEMENT**

The above document describing the benefits, risks and procedures for the research title ***of women living with obstetric fistula*** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

_____ _____

Date Name and signature or mark of volunteer

**If volunteers cannot read the form themselves, a witness must sign here:**

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

_____ _____

Date Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with

Participating in this research has been explained to the above individual.

_____ _____

Date Name Signature of Person Who Obtained Consent

# APPENDIX B

## IN-DEPTH INTERVIEW GUIDE FOR WOMEN LIVING WITH OBSETRIC FISTULA WITHIN THE MUNICIPALITY

**Introduction**

The main objective of the study is to explore the lived experience of women with obstetric fistula in the Wa Municipality. You are assured that all responses provided would be strictly confidential and used only for academic purposes. Please, your anonymity is guaranteed and your participation in the study is voluntary; however, your decision to participate will be very much appreciated. The discussion will take about 30 minutes of your time. Thank you for agreeing to participate in the study. For further enquiries please contact Ms. Gladys on +233(0)243109991.

Time of interview [Begins].....

[Ended].....

Date.....

**SECTION A: BIO-DATA OF PARTICIPATE**

- Participant name/code
- Age of participant
- Occupation of the participant prior to the condition?
- Who do you live with currently?
- What is your marital status?
- If married, do you still live with your husband in the same house?
- If divorced, were you divorced before or after sustaining the condition?

- If divorced, was the condition of obstetric fistula the cause of the divorce?
- How many children do you have?
- How many times have you given birth?
- Do you mean CS or vaginally?

**SECTION B: Experiences Fistula patients face in living with the condition.**

1. Tell me about your condition (obstetric fistula). **Probe for**
    - ✓ What is the nature of the leakage (urine or faeces)?
    - ✓ How did you end up with the obstetric fistula?
    - ✓ Can you tell me more about that particular delivery?
2. Please tell me about your everyday experiences with obstetric fistula

    **Probe for;**

    - ✓ Has the obstetric fistula changed your daily life in any way?
    - ✓ Can you tell me how your life has been affected?
    - ✓ Meeting people in gatherings: e.g., funerals, marriage ceremonies, etc.
    - ✓ Can you tell me the attitudes of friends and family members toward you?
    - ✓ Tell me the family roles you used to play and now?
    - ✓ Tell me about your ability to do work with the fistula?
    - ✓ Can you tell me how the condition has affected your self-esteem?

**Section C: Challenges Fistula patients face in seeking care**

3. Tell me some of the challenges you face as a result of your condition, regarding (**probe for**);

- ✓ Your work
- ✓ You and your husband's sexual relationship
- ✓ Your relationship with friends and family members).
- ✓ What challenges do you anticipate?

**SECTION D; COPING STRATEGIES**

4. How do you cope with the condition **Probe for;**

   Where do get help from?

Is there anything else you would wish to tell me about the experiences of women and Obstetric Fistula?

**Section E**: Any other suggestion for health professionals and people who take care of you?

**Thank you**.

# APPENDIX C

## COVER LETTER FOR ETHICAL CLEARANCE FORM SCHOOL OF NURSING UCC

UNIVERSITY OF CAPE COAST
COLLEGE OF HEALTH AND ALLIED SCIENCES
SCHOOL OF NURSING AND MIDWIFERY
DEAN'S OFFICE

Telephone: 233-3321-33342/33372
Telegrams & Cables: University, Cape Coast
Email: nursing@ucc.edu.gh

UNIVERSITY POST OFFICE
CAPE COAST, GHANA.

Our Ref: SNM/I/4/Vol.1/57

Your Ref:

3rd December, 2018

The Chairman
Institutional Review Board
UCC

Dear Sir,

**APPLICATION FOR ETHICAL CLEARANCE TO CONDUCT RESEARCH: MS. GALDYS SUFUYANI**

We forward herewith the attached application for ethical clearance from the above named level 850 Master of Nursing students with registration number SN/MNS/17/0017 of the School of Nursing and Midwifery for your consideration, please.

Thank you.

Yours faithfully,

Dr. Dorcas Obiri-Yeboah
**DEAN**

# APPENDIX D

## ETHICAL CLEARANCE LETTER FROM IRB UCC

UNIVERSITY OF CAPE COAST

INSTITUTIONAL REVIEW BOARD SECRETARIAT

TEL: 0558093143 / 0508878309/ 0244207814
E-MAIL: irb@ucc.edu.gh
C/O Directorate of Research, Innovation and Consultancy

OUR REF: UCC/IRB/A/2016/297
YOUR REF:
OMB NO: 0990-0279
IORG #: IORG0009096

20TH FEBRUARY, 2019

Ms Gladys Sufuyani
Department of Nursing and Midwifery
University of Cape Coast

Dear Ms Sufuyani,

**ETHICAL CLEARANCE – ID: (UCCIRB/CHAS/2018/23)**

The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for the implementation of your research protocol titled **Lived experience of women with obstetric fistula in the Wa Municipality.** This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

Please note that any modification of the project must be submitted to the UCCIRB for review and approval before its implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

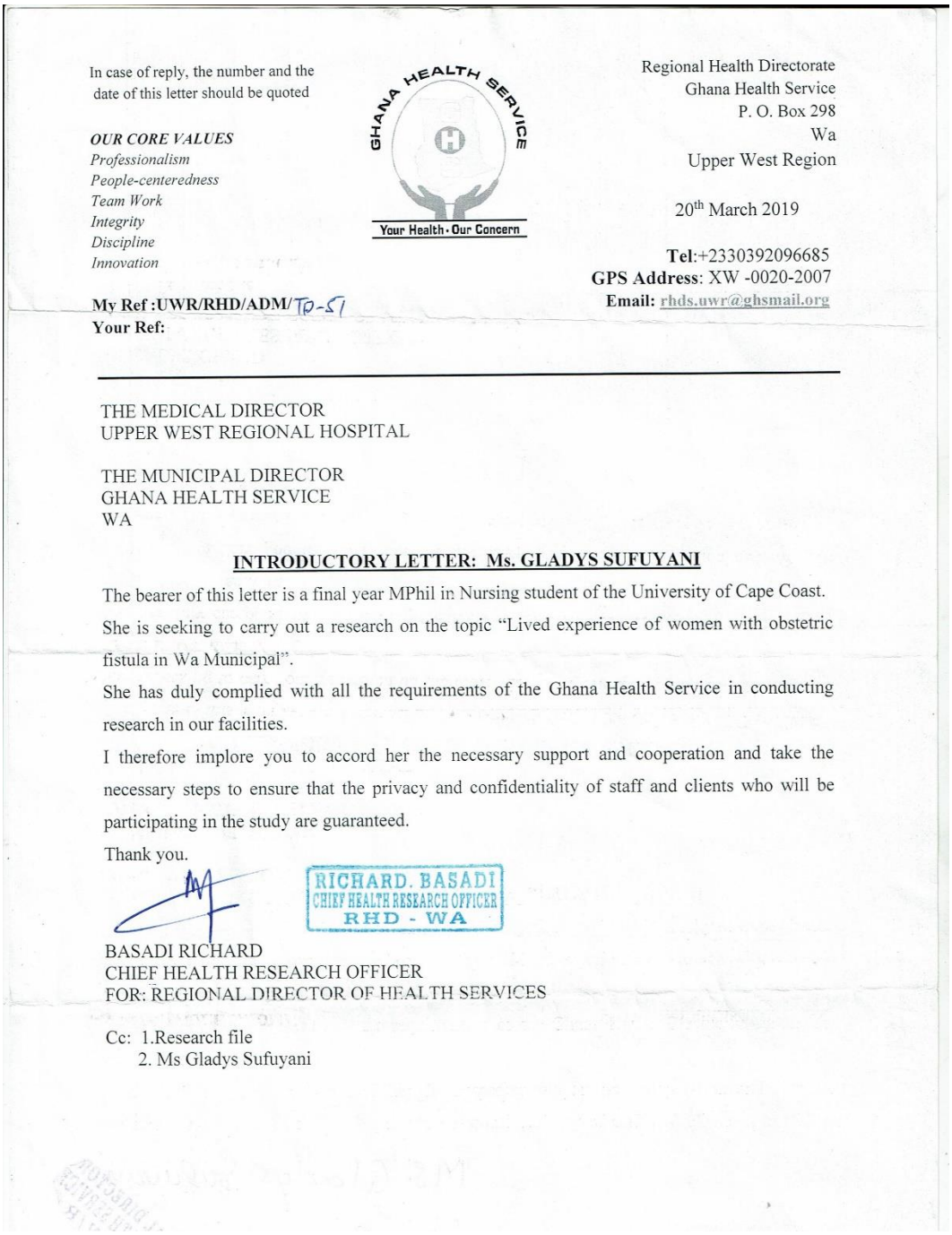
Yours faithfully,

for: Samuel Asiedu Owusu, PhD
**UCCIRB Administrator**

ADMINISTRATOR
ITUTIONAL REVIEW BOARD
JNIVERSITY OF CAPE COAST
Date: 21/02/19

# APPENDIX E

## LETTER FROM THE HEALTH DIRECTORATE



In case of reply, the number and the date of this letter should be quoted

*OUR CORE VALUES*
*Professionalism*
*People-centeredness*
*Team Work*
*Integrity*
*Discipline*
*Innovation*

GHANA HEALTH SERVICE
Your Health · Our Concern

Regional Health Directorate
Ghana Health Service
P. O. Box 298
Wa
Upper West Region

20th March 2019

**Tel**:+2330392096685
**GPS Address**: XW -0020-2007
**Email:** rhds.uwr@ghsmail.org

**My Ref :UWR/RHD/ADM/**TD-51
**Your Ref:**

THE MEDICAL DIRECTOR
UPPER WEST REGIONAL HOSPITAL

THE MUNICIPAL DIRECTOR
GHANA HEALTH SERVICE
WA

**INTRODUCTORY LETTER: Ms. GLADYS SUFUYANI**

The bearer of this letter is a final year MPhil in Nursing student of the University of Cape Coast. She is seeking to carry out a research on the topic "Lived experience of women with obstetric fistula in Wa Municipal".

She has duly complied with all the requirements of the Ghana Health Service in conducting research in our facilities.

I therefore implore you to accord her the necessary support and cooperation and take the necessary steps to ensure that the privacy and confidentiality of staff and clients who will be participating in the study are guaranteed.

Thank you.

RICHARD. BASADI
CHIEF HEALTH RESEARCH OFFICER
RHD - WA

BASADI RICHARD
CHIEF HEALTH RESEARCH OFFICER
FOR: REGIONAL DIRECTOR OF HEALTH SERVICES

Cc: 1.Research file
2. Ms Gladys Sufuyani

# APPENDIX F

## APPLICATION FOR ETHNICAL CLEARANCE

UNIVERSITY OF CAPE COAST, INSTITUTIONAL REVIEW BOARD (UCC-IRB)

University of Cape Coast
College of Health and Allied Health Sciences
School of Nursing and Midwifery
30TH November, 2018

Thro
The Dean
School of Nursing and Midwifery
University of Cape Coast

The Chairman
Institutional Review Board
University of Cape Coast
Cape Coast

Dear Sir/Madam,

APPLICATION FOR IRB CLEARANCE

I am a Master of Nursing Student, and would be grateful if you would review my research proposal on the topic: Lived experience of women with obstetric fistula in the Wa municipality.

Find attached are the necessary document for your review.

Yours Faithfully

.....

Sufuyani Gladys
(SN/MNS/17/0017)